Moving beyond the 'self' in self-management : the role of sport in facilitating transplant recipients' social networks

Bescoby, Carl

Award date:
2021

Awarding institution:
University of Bath

Moving beyond the 'self' in self-management : the role of sport in facilitating transplant recipients' social networks

Bescoby, Carl

Award date:
2021

Awarding institution:
University of Bath

MOVING BEYOND THE 'SELF' IN SELF-MANAGEMENT: THE ROLE OF SPORT IN FACILITATING TRANSPLANT RECIPIENTS' SOCIAL NETWORKS

Carl Bescoby

A thesis submitted for the degree of Doctor of Philosophy

University of Bath

Department for Health

October 2020

DECLARATION OF AUTHORSHIP

I am the author of this thesis, and the work described therein was carried out by myself personally.

TABLE OF CONTENTS

LIST OF TABLES AND FIGURES

Tables

Figures

ACKNOWLEDGEMENTS

I wish to first and foremost thank the participants who generously gave up their time to take part in this study and share their experiences with me. I have come to understand every one of your stories and I know that your transplant journeys will continue to provide hope and inspiration to many others as they have done so for me. Moreover, your determinedness to fulfil life will remain with me well beyond the close of this study.

My special thanks go to my supervisors who have supported my development over the last three years. Their guidance, critical thought-provoking questions and ideas have in no doubt progressed this project towards completion. Thank you to Fiona Gillison and Rachel Arnold who, despite coming on board towards the latter stages of the PhD, have progressed my thinking twofold, and have provided valuable insight and feedback which has developed this PhD further. A special thank you to Gareth Wiltshire, who from the beginning has provided invaluable support, advice and guidance which has been limitless. I am grateful for Gareth's patience with my progression over the years and the trust and freedom he gave me to develop my intellectual thinking and ideas. Thank you for pushing me to be the best that I can be.

I am grateful to the university for providing my studentship, without which I would not have been able to conduct this study. I am also grateful to the PhD cohort within the Health Department who have been an important part of the journey, enriching my experiences over the past three years. I can say with confidence that I now have a great peer support network and I have developed long-lasting friendships.

I would like to thank my family for their continued love, support, and encouragement. I am indebted to my parents who have guided me through the highs and lows, encouraging me to follow my own path and aspirations and supported me financially. Without their support the completion of this thesis would not have been possible. A special thanks to dad for somehow making me feel that it was going to be okay in the end even when I did not think so myself. As you embark on your new journey as a counsellor, I know that you will continue to help and support others as you have done so with me and you will make an excellent practitioner.

Finally, a special thanks to my girlfriend, Kathrin, who has been a diligent proof-reader and sound board and has seen me down the home straight. Your love and support continued to guide me through this tough last year.

ABSTRACT

Background: Within a growing body of literature evidencing the importance of self-management for transplant recipients, research has often accentuated the individual level outcomes influencing generalised self-management programmes. Yet, understanding transplant recipients' social networks may be a useful way of moving beyond the individualised self-management programmes, to consider the wider social context. Sport offers ways to develop social relationships and could offer a useful way of facilitating social network structures that may offer support with illness self-management. Yet, there is very little research exploring the impact of sports participation on transplant recipients' illness self-management networks. The purpose of this study is to investigate transplant recipients' experiences of participation in Transplant Games events for the first time and to understand the impact this may have on their illness self-management networks over time. **Methods:** This study employed a longitudinal qualitative social network approach, combining participant-aided network diagram creations (sociograms) with a series of three interviews over a 12-month duration with an international cohort of transplant recipients. A total of 48 interviews and 32 sociograms were completed between September 2018 and January 2020. Data analysis included thematic analysis of the interview data, visual network analysis of the sociograms and longitudinal analysis of both the social networks visualisations and thematic analysis themes to determine changes over time. **Results:** The findings indicated four types of networks including family-focused, friend-focused, family-friend focused, and diverse-sport focused. Most participants represented either family-focused or friend-focused networks and these two network types were most stable over time. Attending Transplant Games events for the first time, impacted participants' illness self-management networks through the inclusion of weaker ties. Although weaker ties did not impact on the types of networks participants had, they provided useful functions for buffering negative, relational experiences of close ties and offered opportunities to share stories and experience closeness which promoted sense of longevity. Participants perceived taking part in Transplant Games events to positively impact their illness self-management. **Conclusions:** Results contribute to an understanding of how participating in Transplant Games events may impact on participants' illness self-management networks. This study moves beyond the 'self' in the self-management and towards an understanding of sport as a psychosocial tool to build and develop illness self-management networks. This study develops and details novel methods in the qualitative social network approach.

CHAPTER 1: INTRODUCTION

1.1 Background

Acute disease or chronic illness could lead to organ failure which may require lifelong treatment or transplantation. This could cause an individual's world to become disorganised and preoccupied with making decisions about their health and adjusting to changes in functionality, independence, and control (Schulz & Kroencke, 2015). This may also involve dealing with changes in health, life and shifting roles and responsibilities with family and loved ones. While interruptions to individual life are common with most chronic illnesses, individuals awaiting a transplant have specific disruptions. These include the constant fear and uncertainty of waiting for a suitable donor whilst the risk of morbidities and mortality continues to increase (Brown, Sorrell, McClaren, & Creswell, 2006). However, dependent on the illness and affected organ, some individuals can maintain a reasonable level of health whilst waiting for a transplant. For example, individuals waiting for a kidney donor with end-stage kidney failure may engage in dialysis treatment which partially fulfils the job of their dysfunctional kidneys. Whilst this is an available treatment and maybe a more realistic and viable treatment for some individuals, it requires dedicated routines and serious time commitments (Shaw 2015). For some, organ failure or acute disease may be gradual, occurring after years of managing a slow decline in health. For others, this could be sudden ill health or acute trauma which requires immediate medical intervention in the form of solid or non-solid transplantation.

Solid and non-solid organ transplantation is a cost-effective treatment for end-stage organ failure or disease (World Health Organization, 2019). Solid-organ transplants include heart, lung, liver, pancreas, kidney, bowel, and corneas whereas non-solid transplantation includes either bone marrow or stem cell transplants. Acute organ failure or chronic diseases such as end-stage liver disease or end-stage kidney disease may require an organ transplant and cancers such as leukaemia, lymphoma or myeloma may require bone marrow or stem cell transplants as possible treatments. In both cases, solid and non-solid transplants may be offered as the most viable, suitable, and cost-effective treatment (World Health Organization, 2019). Transplants, solid or non-solid, can come from live or deceased donors although, the most common procurement of organs involves the removal of organs from a deceased person following legal consent (World Health Organization, 2019). Sources of living donors are usually attributed to the familial relationships (Tong et al., 2012), paired exchange programs or what the transplant community would term 'altruistic donation' (Jasper, Nickerson, Ubel, & Asch, 2004). This demonstrates how individuals who have various chronic illnesses have

diverse experiences when it comes to transplantation which may impact their treatment and management approaches.

In the 1950s, transplantation procedures were considered experimental, a long way off therapeutic and routine. This was until surgical and immunosuppressant advancements in the late 1970s reduced the significant rejection rates associated with these early procedures (Lock, 2002). The new advancements in surgical techniques and medical technology not only reduced the number of individuals waiting for a transplant (Scientific Registry of Transplant Recipients, 2017), making organ procurement central to the ongoing organ shortage crisis, but it also progressed transplantation towards a routine procedure increasing success rates and success stories. Approximately 140,000 solid organs are transplanted worldwide each year with the number of non-solid transplants set to surpass this figure (Global Observatory on Donation and Transplantation, 2019). Across organ transplantation, kidneys are the most transplanted organ with nearly 90,000 transplants performed each year globally, followed by over 30,000 liver transplants. In the UK alone, around 5,000 transplants have been performed this last year with this number set to rise (NHS, 2020). Whilst these figures are a good indication of an organ procurement system that works well, with transplant figures seeing a gradual increase over the more recent years, there is still a major shortage of available organs to meet the current demand. For example, in the UK approximately 6,000 individuals are currently on the waiting list for a transplant, with approximately three people dying each day 'waiting for the call' (NHS, 2020). While efforts continue to close the gap between the demand and availability of organs through donation awareness campaigns and policy changes, the current organ shortage has accentuated the focus on the longevity of recipients' lives who are fortunate enough to receive a transplant.

As described so far, transplantation is understood as a medical treatment. However, transplantation can also be considered as a chronic condition in itself which requires careful management, given the complex and life-long medical regime transplant recipients have to adhere to (Iglesias et al., 2020; Mathur et al., 2014). As a growing population, transplant recipients must engage with ongoing self-management practices to prolong health, reduce symptoms of illness, manage implications of immunosuppressive therapies, manage the adverse side effects of medication, and maintain physical functioning whilst also navigating the complex psychosocial impact of receiving the 'gift of life' (Moini, Schilsky, & Tichy, 2015). As such, self-management refers to the daily activities implemented to reduce the impact of chronic illness on physical functioning, health status and as a way of controlling for psychosocial outcomes (Gallant, 2003). Whilst the physical functioning is an integral

component of self-management, the psychosocial outcomes may also contribute to chronic illness experience and impact on transplantation outcomes and should not be considered secondary outcomes (Novak, Costantini, Schneider, & Beanlands, 2013).

Despite an increasing emphasis on psychosocial outcomes, self-management programmes have often targeted individual level outcomes including behavioural and educational components often reflecting an increasing emphasis on self-efficacy (Koch, Jenkin, & Kralik, 2004) marginalising the sociological outcomes (Rogers, Gately, Kennedy, & Sanders, 2009). In addressing these concerns, research has moved towards understanding the social context and the role of informal networks within self-management outcomes and interventions (Vassilev, Rogers, Kennedy, & Koetsenruijter, 2014; Vassilev et al., 2011). Further, research has addressed the emotional and social challenges including shifting identities and social role responsibilities associated with living with a transplant and navigating self-managing health outcomes (Bogue Kerr, Soulière, & Bell, 2018; Crowley-Matoka, 2005; Svenaeus, 2012). Here, the trajectory of chronic illness and transplantation is influenced by and influences the psychosocial outcomes associated with self-management including the personal communities and social networks of transplant recipients navigating their health. Therefore, understanding transplant recipients' social networks may be a useful way of moving beyond the individualised self-management programmes, to consider the wider social context and the collective role of others as has been explored in chronic illness management literature in recent years (Vassilev, Band, Kennedy, James, & Rogers, 2019; Vassilev et al., 2013).

Advancing the sociological understanding of self-management may also highlight the negative influence transplantation and managing chronic illness may have on everyday interactions such as close family relationships (Gallant, Spitze, & Prohaska, 2007). This might also offer new points of connection for understanding the moral relationships with donors (Fox & Swazey, 2002) and the obligation transplant recipients may feel to give something back (Heinemann, 2014). Understanding transplant recipients' illness self-management networks may offer insight to how obligations are fulfilled or how giving back is spread through networks. Further, the gratitude transplant recipients may feel after having received a lifesaving transplant could influence their behaviours, something that is embedded within their social relationships. This could be important to consider in the context of understanding self-management and specifically transplant recipients' lifestyle behaviours such as commitment to physical activity, exercise, and sport as a social practice.

Research has found participating in sport to be linked with the development of social relationships (McDonough, Ullrich-French, & McDavid, 2018). Furthermore, the social value of sports events may enable relationships to form that would not normally be formed (Chalip, 2006; Roche, 2002). As such, it is plausible that sport could be a useful way of building and facilitating social network structures that may offer support with illness self-management. Sport offers the opportunity to establish valuable social networks and to develop a sense of agency and belonging within a community (Perks, 2007). In this way, social networks may be beneficial for navigating the illness trajectory towards restructuring the self and social positioning, and as a way of fulfilling the moral obligations as a transplant recipient. Additionally, participating in sport may well improve health practices, psychosocial functioning and improve overall quality of life of transplant recipients through facilitating social relationships. Moreover, sport may offer a way of exploring the social context of self-management and may also provide a future focus for practitioners to consider interventions that encompass psychosocial outcomes whilst moving beyond individualised programmes of care.

On this basis, I suggest a focus within this study on sport through exploring transplant recipients' participation in Transplant Games events which offers points of connection between social networks, illness trajectories, psychosocial and self-management outcomes. The Transplant Games was conceived by Maurice Slapak, a surgeon from Portsmouth, with a vision to create an event to promote the benefits of organ transplantation and raise awareness for organ donation. This was through normalising end-stage organ failure rehabilitation and demonstrating that transplant recipients can resume a level of physical functioning post-transplant. The experience of participating in Transplant Games events includes taking part in national-level competitions such as the British Transplant Games within the UK (Transplant Sport UK, 2020) or international competitions such as the biannual World Transplant Games (World Transplant Games Federation, 2019). These events offer Olympic style competitions where regional hospital teams or countries - in the case of the World Transplant Games - compete against each other (Griffin, 1990; Slapak, 2005). The World Transplant Games include some 60 countries with over 3,000 competitors who take part in over 50 events including athletics, swimming, golf, running road race, cycling, badminton, table tennis, volleyball, pétanque, tennis, squash, and tenpin bowling. Participation in Transplant Games events are open to transplant recipients aged 4-80 years that have undergone solid or non-solid

transplants including liver, heart, lung, kidney, pancreas, and bone marrow and all athletes go through a health clearance before involvement (World Transplant Games Federation, 2019).

There has been wide-reaching literature supporting the impact of the Transplant Games on transplant recipients' physical functioning (Deliva et al., 2014; Janaudis-Ferreira et al., 2019), physical activity levels (Mosconi et al., 2014; Mosconi., Roi, & Stefoni, 2011), quality of life (Cicognani et al., 2015; McGee & Horgan, 1996; Painter & Marcus, 2013), and psychological wellbeing (Atamañuk et al., 2017; Johnson, Hinic, Billstrom, & Gabel, 2013). While these studies offer some useful insights into transplant recipients' experiences of sport, the knowledge remains partial with scope to move beyond the physical and psychological components towards previously unexplored connections between these outcomes from a psychosocial standpoint.

With an emphasis on Transplant Games events, within this study I will focus on how transplant recipients' social networks are impacted through participating in sport and in what way sport may contribute to their psychosocial and self-management outcomes. In doing so, I hope to make a meaningful contribution to previous literature and address the scant research on the psychosocial perspective of sport. The contributions of this study will hope to extend literature and establish how sport could be used as a tool to improve the lives of transplant recipients and enhance their experiences of self-management. Moreover, in establishing the social context of taking part in sport, this study will hope to address the current gaps within the literature. In doing so, I hope to offer an evidence base for future practitioners and policy makers to move beyond the individualised notions of self-management towards considering wider psychosocial implications.

1.2 Aims and research questions

The aim of this study is to investigate transplant recipients' experiences of participation in Transplant Games events for the first time and to understand the impact this may have on their illness self-management networks over time. In doing so, I will examine how shared experiences and meeting similar others influences how transplant recipients perceive their illness trajectory and self-management experiences, as well as better understand how this evolves over time. The specific research questions for this study are as follows:

1. What characterises the illness self-management networks of transplant recipients who have participated in Transplant Games events for the first time?
2. How do the illness self-management networks of transplant recipients who have participated in Transplant Games events for the first time change over the 12-months following participation?
3. Why does taking part in Transplant Games events impact illness self-management networks?
4. How do these factors change over the 12-months following participation in Transplant Games events?

1.3 Structure of the thesis

Following on from the introductory chapter, Chapter 2 provides a review of the literature in line with the general aims of the thesis. I will examine previous research outlining the self-management experience of chronic illness and transplantation and highlight research which emphasises how the individual level focus has promoted self-management programmes and interventions, ignoring the wider social context. Within this chapter, I will then review literature examining the experiences and challenges associated with chronic illness and transplantation before outlining research focused on the wider social understanding of the transplant self-management experience. I will draw points of connection between this literature before reviewing research which has discovered the usefulness of sport as a way of navigating chronic illness, restructuring a future self, and building social networks important for self-management outcomes. Finally, this chapter will draw on literature focused on Transplant Games events which have established post-transplant outcomes and self-management experiences highlighting the gap of focusing on Transplant Games events from a psychosocial perspective. Chapter 3 then presents the methodological approach and outlines, with critical appraisal, the specific methods used. This chapter will be used to reflect on the data collection process and provide justification for its appropriateness.

Within Chapters 4 to 7, I present the findings of the study. Chapter 4 will outline the characteristics of participants' social networks in the form of network typologies to address the

first research question and within Chapter 5 I will display the longitudinal component of participants' social networks to discover how the structural elements of networks change over time to answer the second research question. Chapter 6 then concerns the third research question where I explore the interviews using thematic analysis. Within Chapter 7, I introduce the longitudinal component of the thematic analysis using sequential matrices and participant case studies to address the fourth and final research question to illustrate changes within the themes over time. In considering these findings, Chapter 8 offers a discussion where I return to the wider aim of the thesis and bring together all the findings to illuminate participants' experiences of participating in Transplant Games events for the first time and its impact on participants' illness self-management networks over time. Further, this chapter will highlight how these findings relate to previous research and how they have addressed the research questions. In considering the contribution of these findings to existing literature, the chapter will also outline the wider implications and contributions of this research study. Finally, Chapter 9 will provide a conclusion where I summarise the thesis and offer some reflexive comments about the study in its entirety whilst also providing suggestions for future research.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The purpose of this chapter is to establish current knowledge so that it can be built upon and further to identify the gaps within the literature to highlight the place for this thesis in expanding this body of research. Within this chapter, I review research concerning the self-management of chronic illness experience for transplant recipients to understand how the individual level focus on the mechanisms of self-management has promoted individualised self-management programmes. Here, I acknowledge the paucity of research considering the wider social context and argue for a greater focus on the relational resources within individuals' social networks in shaping self-management practices. I will then review research outlining the challenges associated with managing chronic illness and transplantation including the disruption to individuals' biographical selves and the impact of illness on identity when navigating a sense of being between illness and health. This chapter then addresses literature pertaining to the wider social understanding of the transplant self-management experience which integrates the individual level experiences with the illness and transplant trajectories. I will position this research within the relational and social aspects of everyday life. In reviewing relevant research in this way, I hope to outline previously unexplored connections with the wider sport literature, and in doing so, I hope to create links between the role of sport in offering a wider social understanding for managing transplant and self-management outcomes. Here, I will outline literature supporting the usefulness of sport as a way of navigating illness and the transplant trajectory. Further, I will discuss the research that promotes sport as a way of restructuring a future self. I will then review the literature that has examined the impact participation in Transplant Games events has on transplant recipients' post-transplant outcomes and self-management experiences. Finally, this chapter will highlight the gaps within the literature which will help frame the focus and originality of this study.

2.2 The 'self'-management of chronic illness for transplant recipients

With a growing population of patients going through successful transplant procedures there has been a shift in emphasis towards self-management within healthcare delivery in recent years. This has been informed by policy makers attempting to reduce the demands on health services. Furthermore, transplantation is often viewed as a treatment rather than a cure due to the demands of lifelong monitoring of the transplanted organ. For example, transplant recipients

are faced with daily monitoring and adherence of immunosuppressive treatment, and managing the adverse side effects of the medical regime such as diabetes, weight gain or abdominal discomfort, dependent on medication (Moini et al., 2015). Further, recipients are faced with managing the increased risk of morbidities such as heart disease (Stoumpos, Jardine, & Mark, 2015) as well as the possibility of graft failure and or rejection. For a transplant recipient, the failure or rejection of a transplanted organ could lead to the rapid decline in health, the return to pre-transplant illness, reduced function and longevity of the transplanted organ, or the need for further transplants in the future. Furthermore, the return to illness may inflict reduced mobility and functioning required for daily tasks and may necessitate an increase in self-management procedures. Therefore, transplant recipients face a complex and continual need to manage their ongoing chronic illness and multi-morbidity which requires control, autonomy and decision making beyond merely adhering to a prescribed behavioural regimen (Gallant, 2003).

The effectiveness of chronic illness self-management has been primarily determined by physical outcomes. That is, the emphasis has been on improving the physical functioning of people living with chronic illness and as a way of reducing co-morbidities (Iglesias et al., 2020). However, the psychosocial outcomes may also be an important component of self-management which may contribute to the effects of chronic illness (Novak et al., 2013). Here, it is important in the context of this thesis and literature review to describe what is meant by self-management given that multiple definitions are used within the literature and no single definition exists. As such within this thesis, I refer to self-management as "a normal part of daily living, which involves the actions individuals take for themselves and their families to stay healthy and to care for minor, acute and long-term conditions" (Osborne, Jordan, & Rogers, 2008, p. 224). Further, self-management consists of the daily activities to minimise the impact of chronic illness on physical functioning and health status as well as controlling for the associated psychosocial outcomes (Gallant, 2003). These definitions are consistent with Corbin & Strauss (1988) conceptualisations of self-management which considered three processes including medical, role and emotional management. The authors integrated psychosocial aspects of self-management to include the uncertainty of chronical illness and the lifestyle modifications involved with managing illness. It is understanding these wider psychosocial outcomes associated with self-management which may aid in understanding how these impact on and are impacted by the physical functioning of transplant recipients and their ongoing health status.

A growing body of literature has demonstrated the improved psychological outcomes associated with successful self-management (Clark et al., 1991). The significant impact successful self-management has on psychological outcomes has promoted its foci alongside formal care providers (Clark et al., 1991; Fisher et al., 1997; Grady & Gough, 2014). As transplant recipients navigate life after transplantation, they may face difficulties with psychological functioning which raises important questions for understanding the role of psychological outcomes post-transplantation. Research has highlighted that better psychological outcomes are achieved when individuals can successfully self-manage long-term illness (Anekwe & Rahkovsky, 2018). Clark et al. (1991) suggest self-management involves making informed decisions regarding one's care, performing specific self-management activities as well as applying the necessary skills for monitoring psychosocial functioning. Within this, early research has focused on self-regulation which includes self-monitoring, goal setting, decision making and action planning as a way of increasing psychological functioning and adherence to self-management behaviours (Boekaerts, Zeidner, & Pintrich, 1999; Creer, 2000; Tobin, Reynolds, Holroyd, & Creer, 1986; Vohs & Baumeister, 2016). Here, self-regulation is situated within the social-cognitive theory (Bandura, 1999; Bandura & Walters, 1977) which considers an individual's thoughts, cognitions, and behaviours through the interaction of the physical and social environment. As it is referred to here, self-regulation enhances the self-efficacy of individuals managing chronic illness, increasing engagement in self-management behaviours such as adhering to interventions or self-care programs. What is clear from the focus of the research highlighted here is the influence of psychological outcomes on self-management, reciprocally influencing each other.

Self-management programs have often reflected an increasing emphasis on developing self-efficacy with more individualised programmes informed by social cognitive theory (Koch et al., 2004). That is, individuals are encouraged to manage their chronic illness as they become 'experts' over time. For example, the Expert Patient Program (EPP) offers a generic skill-based programme for patients with chronic illness to build competency in several areas including nutrition, exercise, informed decision making, and working with healthcare professionals. The main goal of the EPP is to encourage individuals to gain confidence in their ability to manage their own health recovery (Health, 2001; Jeffries et al., 2015). Within the transplant literature, evidence has demonstrated the positive influence self-efficacy has on self-management outcomes. For example, Weng, Dai, Huang, and Chiang (2010) found self-efficacy to positively influence problem-solving, patient-provider partnerships, and self-care behaviour

dimensions of kidney transplant recipients' self-management. Here, the authors called for interventions to incorporate self-efficacy to improve patients' self-care behaviour which supports the application of the EPP. However, the emphasis on self-efficacy to influence behaviour has limited the application of wider psychosocial outcomes.

Offering a different perspective on self-management, Rogers (2009) notes the emphasis on self-efficacy within self-management programmes which has reinforced self-efficacy as the most important patient outcome, marginalising other considerations. Rogers et al. (2009) recognised the disregard for the social needs of patients which have not been deemed integral within the literature and the EPP programme to date. Rogers (2009) acclaimed that this has been detrimental to the effectiveness of self-management programmes which heavily rely upon social comparison between patients to mediate self-efficacy. Indeed, it is argued that the impact of social comparison has not been considered beyond its mediating role with self-efficacy. That is, the impact of social comparison in mediating self-efficacy would suggest that patients gain confidence in their abilities to self-manage when comparing with good example patients (Kennedy, Rogers, & Bower, 2007). However, this does not consider the negative impact social comparison may have on individuals ability to self-manage. For example, upward comparisons which induce uncertainty regarding one's health may cause disruptive emotional responses (Gately, Rogers, & Sanders, 2007; Rogers et al., 2009). Therefore, programmes such as the EPP and the emphasis on self-efficacy and the role of social comparison may be detrimental to individuals' mental health and psychological functioning and should be considered as context dependent.

Another criticism of the EPP is that the programme imposes an image of a 'good self-manager' to create coherence in social values and identities between patients. However, as Rogers (2009) points out 'identity cannot be prescribed' in this way and needs careful consideration. Furthermore, identities are mediated through the social environments which individuals with chronic illness must navigate. Here, social identity theory considers the notion that cognitive identity is formed through contexts which could include chronic illness. Yet, anticipated chronic illness can limit the impact on an individual's identity and instead could be considered as part of the normal life cycle (Sanders, Rogers, Gately, & Kennedy, 2008).

Overall, this perspective from research suggests a lack of consideration for the sense of self, identity formation, and variation in how individuals navigate social roles along with their relationships throughout illness which has therefore limited the applicability of individualised

self-management programmes such as the EPP. These criticisms are warranted given the emphasis on individual mechanisms and the over-emphasis on behaviour-based approaches which have often overshadowed alternative approaches. Further, these criticisms have led to research calling for a wider focus across the social context for understanding self-management behaviour.

In support of these calls is the work of Schulman-Green et al. (2012) who conducted a meta synthesis of qualitative research assessing patients' perspectives of the tasks and skills required for self-management. The authors found that this involved three areas including *focusing on illness needs*, *activating resources,* and *living with a chronic illness*. The first area identified by the authors - focusing on illness needs - considered the ability individuals acquire to manage the demands of chronic illness such as developing knowledge about their condition and medication. The second area was activating resources which referred to the ability to identify and mobilise social, healthcare and community support to aid self-management outcomes. In support of this Gallant (2003, p. 171) stated that "self-management does not occur in a vacuum but rather in a context that includes formal health care providers, informal social network members, and the physical environment". The third area of Schulman-Green et al. (2012) conceptualisation of self-management processes - living with a chronic illness - considered the integration of illness into daily routines and coping with the emotional demands to rediscover the self and find meaning in the illness experience. Here, living with a chronic illness is centred around adjusting to illness and identifying the change and loss to physical function, roles, and identity as a way of coming to terms with the new self. Thus, understanding these components with living with an organ transplant and the transformation of the self is key to forming an understanding of where the social context is situated and how it may interact as part of these experiences.

Indeed, the social context in terms of informal social networks and the role of others within self-management has been largely absent within the literature up until recently. Vassilev et al. (2011) stated that; "the design of long-term condition self-management interventions have given little more than a passing wave to social context, and the role of others in shaping and supporting self-care practices" (pg.60).

Taking the social context seriously, is about offering a different viewpoint (a social perspective) that can help to develop alternative questions and considerations about self-management across the micro, meso and macro level (Vassilev et al., 2014; Vassilev et al.,

2011). Research within transplantation self-management has been hesitant in providing a different viewpoint (Been-Dahmen et al., 2018). Thus, research is needed to move beyond the individual model to understand how social influences may impact on the overall patient experience, providing support for a wider social context approach to improve psychosocial functioning implicit to overall self-management outcomes (Bury, 1982; Bury, Newbould, & Taylor, 2005; Frost, Grose, & Britten, 2017; Townsend, Wyke, & Hunt, 2006).

2.3 The wider social context of living with a transplant and the role of others

Self-management as a collective process has gained increasing recognition as research has turned to understanding the role social networks and personal communities play in mobilising resources important for self-management outcomes (Vassilev et al., 2014). People living with chronic illness may withdraw from social activities as interactions with others change through managing varying social roles with the shifting demands of illness over time. Further, the shifting roles and identities are also in part mediated through relationships with others and the social environment (Vassilev et al., 2014). Social networks are constantly navigated as individuals manage the trajectory of their illness which can contribute to self-management as resources are drawn from network members offering and providing support work. To better understand the wider social context of transplant recipients' self-management experiences, I draw inspiration from the illness trajectory literature and the influence of social networks within the disruption of chronic illness. It is here where I depart form the individual level focus of self-management and look at the wider relational and social network perspectives.

Glaser and Strauss (1980) developed the concept of the 'illness trajectory' as a way of determining and defining the constraints of illness. The illness trajectory concept moves beyond the medical description of illness to encompass related work and how it impacts on relationships of those carrying out the work which ultimately impacts on the course of an individual's illness (Schneider, Conrad, & Gallagher, 2011). Being altered physiologically influences identity, social interaction and social experiences (Cormier, Gallo-Cruz, & Beard, 2017). Here, the social interaction and social experiences are formed through the negotiation of relationships with others through related work. The related work that Glaser and Strauss (1980) conceptualised within illness trajectory has been defined and applied by Corbin and Strauss (1985) who introduced three types of work when managing illness in daily life:

1. Illness work, involving regimented work, prevention and management of crisis, symptom management ,and diagnostic related work.
2. Everyday work: involving essential day to day tasks including housekeeping, marital work, occupational work, childcare, and other activities such as eating.
3. Biographical work, which refers to the coming of terms with oneself, acknowledging the consequences of illness, and reconstructing the future.

Corbin and Strauss's (1985) conceptualisation of the illness trajectory proposed that illness work and everyday life work required interactions with family members, friends, and health professionals. They go on to suggest that illness trajectories may be apart from everyday life which can change over time from day-to-day. That is, the work performed each day can vary in the time it takes to complete, changes in the difficulty in performing the task, and the consistency at which it is performed. Corbin (1987, p. 278) stated that; "the main issue for people who are chronically ill is not sickness but their body failure and what it does to their activities and their lives". That said, biographical work is about coming to terms with the consequences of illness to reconstruct the stories of the future self. Frank (1998) suggested that stories of illness can be two things at once – a personal story where reconstructing of a damaged-self takes place, or a social one where reconstructing the self takes place in the context of communities lived in, or ones returned to after illness.

The types of work proposed within Corbin and Strauss's (1985) illness trajectory have been supported by more recent research examining the social functioning of transplant recipients. Cavallini, Forsberg, and Lennerling (2015) found five key aspects of social functioning which included work, education, daily activities and leisure, social adaptation, and barriers. Specifically, social adaptation included the importance of social support and the reintegration within social networks for transplant recipients. Here, family and friends were considered the most important to social adaptation with spouses and children also central to this (Forsberg, Cavallini, Fridh, & Lennerling, 2016). Social adaptation was part of the transition from chronic illness through to recovery, integral to the long-term outcome of transplantation and therefore part of negotiating the illness trajectory. Furthermore, Lundmark, Lennerling, Almgren, and Forsberg (2016) found that the recovery trajectory of recipients included physical, psychological, and social recovery. Specifically, social recovery consisted of the drive for independence and the reliance on family and friends for instrumental support which can be likened to everyday work. Consistent across these studies was the role close tie

support played in transplant recipients' recovery post-transplant. Here, it was the role of family and friends that contributed to the illness work, everyday work, and biographic work in line with previous literature (Corbin & Strauss, 1985; Glaser & Strauss, 1980).

Whilst there exists scant literature specific to transplantation that has used Corbin and Strauss's (1985) illness trajectory and classification of work to explain the self-management process, research further afield within the chronic illness literature can help explain its application (Vassilev, Band, et al., 2019; Vassilev et al., 2013; Vassilev et al., 2014; Vassilev et al., 2011). For example, Vassilev et al. (2013) took a network approach to understand network members that were important support providers for those living with chronic illness. The authors used similar conceptualisations of the domains of chronic illness work including illness work, everyday work, and emotional work (which included the biographical dimension). Vassilev et al. (2013) used these classifications of work to understand who the support providers were that contributed to chronic illness work. Findings indicated that partners and family members provided the most support across all the domains of work. Further, healthcare professionals and friends were the next most important contributors perceived by the participants in their study. The claims made by Vassilev et al. (2013) here are supported by earlier work (Gallant, 2003; Gallant, Spitze, & Grove, 2010; Gallant et al., 2007) which identified the important role informal network members play in the self-management and care of the individual. These informal networks consist of family and extended network members. Further, the importance of these informal network members has been accentuated in previous research highlighting the role of family (Rosland, Heisler, Choi, Silveira, & Piette, 2010) and friends and neighbours (Edwardson, Dean, & Brauer, 1995) for managing chronic illness. Vassilev et al. (2013) moved beyond highlighting the importance of social networks as a way of just describing the social context towards understanding the dependencies and characteristics of relationships within a network and its influence on different types of illness work. This study goes beyond the individual responsibility of self-management and reports how various network members are called upon to deal with illness-specific problems. Thus, making a case for wider community engagement as a way of collectively managing illness through facilitating and offering types of work.

A key finding from the Vassilev et al. (2013) study was the value attributed to being able to access and mobilise a diverse set of relationships. Here, weaker ties influenced help-seeking and influenced diverse information within a network which resulted in greater access of resources for illness management. Vassilev et al. (2013) explained this in terms of these

weaker ties being connected to 'networks of networks' which assisted in diversifying information and creating greater availability of resources. Furthermore, these diverse networks may offer everyday work and emotional work through adaptive support within a network. The authors found how weaker ties may act as substitutes for emotional work, demonstrating how certain types of work are dispersed through diverse and varied networks. That is, emotional work was more likely to be dispersed throughout the network where individuals would seek contributions from a wide range of network members which could be situated outside their close ties. These findings suggest that being meaningfully engaged in activity outside close family and friend networks, which offers connection with wider support networks, may offer more emotional support which in turn may enhance health related support as well as the ability to adapt to future health practices (Vassilev et al., 2011).

The influence of weaker ties in offering types of work demonstrated in the Vassilev et al. (2013) study provides support for the well-known network concept of the strength of weak ties (Granovetter, 1977). Granovetter (1983) posits that weaker networks with varied characteristics promoted greater assistance when adjusting to change. Here, change is in managing illness and the illness trajectories whereas assistance refers to the types of work. This early work by Granovetter (1977; 1983) has since prompted further research looking to understand the role of informal support and weaker ties in providing types of illness work and self-management support (Allen, Vassilev, Kennedy, & Rogers, 2016; Crotty et al., 2015; Rogers et al., 2014; Sanders, Rogers, Gardner, & Kennedy, 2011; Vassilev et al., 2016). Overall, weaker ties not only offer types of work, but they offer a way to build diverse networks which may be beneficial to self-management outcomes.

Rogers et al. (2014) found that weaker ties were more durable than stronger ties and that weaker ties were facilitated through reciprocity and personal exchange which reduced the guilt of those chronically ill receiving the support. Thus, enabling weaker ties to play a central role with illness management. Further, weak ties avoided the negativities associated with dependency and intimacy and could form a clearer reciprocal exchange relationship. The authors conclude with suggesting formal healthcare systems should incorporate weaker tie facilitation through community-based involvement. This may build a case for the role of sport and specifically the Transplant Games as a social activity to facilitate weaker ties important for self-management. Similarly, Allen et al. (2016) found that online communities gifted illness work and emotional support and facilitated weaker ties, providing an opportunity to build diverse networks to support illness management. Further, a more recent study from the same

authors found how online communities would be drawn from for support when offline communities were deficient and as such these online communities acted as a substitute for closer intimate ties (Allen, Vassilev, Kennedy, & Rogers, 2020). Previous research has extensively examined the positive impact of social networks in facilitating and providing types of chronic illness work and the role weaker ties play in substituting and buffering close tie support. Yet, there may be opportunities to give further attention to the negative impact of network members, specifically that of close intimate ties.

Research has shed light on how chronic illness influences how support is sought through social networks and how this may negatively influence everyday interactions with informal networks including family members or close ties (Gallant et al., 2007; Shaw., Brown, Khan, Mau, & Dillard, 2013; Vassilev et al., 2014). Merleau-Ponty (2012) stated that individuals often experience a distance from others who do not experience the same concerns as them. That is, the experience of illness, which is subjective and highly individualised, is not relatable to others and as such engaging with others becomes difficult due to these perceptions. Individuals have an innate relationship with their own bodies and so their perceptions of their own health may clash with others. Further, others' perception of an individual's health may also influence how they feel about it. Thus, the individual experience of illness seems to distance oneself from others as perceptions of illness vary between ties. Conversely, shared experience with others going through similar challenges may draw individuals closer and therefore promote the strength of weaker ties.

As social networks are likely to evolve over time (Vassilev et al., 2014), weaker ties are more interchangeable than family ties (Atkinson et al., 2009) which highlights the need to focus on the negative impact these close ties may have on illness management over time. That is, close tie relationships are harder to change within a network given the importance and embeddedness usually attached to these ties. As such, the impact of these close ties is significant to the illness management outcomes, especially if the impact is negative. Therefore, research attempting to better understand the negative influences of important and close family members may help further illuminate how networks impact self-management. Piette, Rosland, Silveira, Kabeto, and Langa (2010) found that family responses which included overprotective, controlling, and distracting behaviours negatively influenced illness management outcomes. These negative responses support the early work of Bury (1982) who found that chronic illness impacts existing relations specifically with emotional exchanges which can negatively impact on individuals. Similarly, Brännström, Ekman, Boman, and Strandberg (2007) found that those

offering care to loved ones struggled to keep everyday life normal and the constant threat of the worsening health of providing care produced feelings of uncertainty and anxiety. In further understanding the role of others within transplant recipients' self-management, I turn attention to the transplant trajectory proposed by Wainwright (1995).

Although the illness trajectory and the development of the types of work by Corbin and Strauss (1985) has been widely applied across chronic illness research as outlined above, there exists a paucity of research that has used these illness conceptualisations within transplant recipient populations to understand the role of others and social support networks. Although many similarities exist between transplant recipients and other chronically ill populations such as the need to manage health outcomes, subtle differences may occur which require further investigation. Wainwright's (1995) five-stage transplant trajectory includes: receiving the transplant, improving in hospital, improving at home, feeling well again, and reciprocating. Improving at home included needing and receiving support from others as they moved towards managing post-transplant outcomes at home away from formal healthcare providers. This stage consisted of the role of close support network as well as the role of the individual to manage chronic illness. Furthermore, this involved reclaiming previously held social roles and acquiring new ones navigated through support received from other recipients within patient support groups. Here, feeling well again involved a collective approach and wider engagement with others. Despite this, an early study by Melzer, Leadbeater, Reisman, Jaffe, and Lieberman (1989) considering the role of social networks within adolescents with end-stage renal disease that had received a transplant found that kidney transplant recipients had fewer individuals in their total network post-transplantation, although family members comprised a greater proportion of their network. Findings suggested that practitioners should encourage engagement in activities for transplanted renal patients and related peers which will lead to independence from family as weaker ties develop.

Two key stages within Wainwright (1995) transplant trajectory of relevance to this PhD thesis are the final two stages of 'feeling well again' and 'reciprocating'. Feeling well again involved becoming a new person, planning-ahead and considering hidden illnesses. It was moving between being healthy and ill that occupied this stage within the transplant trajectory which can be likened to the concept of transliminality and the identity challenges discussed above within the literature concerning living with an organ transplant. The final stage of reciprocating described the need to give back as recipients attached their recovery motivations to doing so for their families and for the medical staff that supported them throughout their

journey. While the chronic illness literature has widely supported the concept of reciprocity to reduce guilt in receiving support, transplant literature has also provided support for this. For example, Heinemann (2014) examined reciprocity between patients and families and the web of relations consisting of informal care to highlight the moral obligations recipients carried as they looked to resume their caring duties post-transplant. Here, transplantation offered an opportunity to resume normal functioning to fulfil these obligations of care within their social roles. It is the network of obligations and reciprocal webs of care within which transplant recipients were embedded. The authors concluded by noting that transplantation is a social phenomenon situated at a level of moral exchange. Furthermore, part of reciprocating at this stage of Wainwright (1995) trajectory was through providing support to similar others as a way of giving something back. This provides support for Rogers et al. (2014) in how reciprocal exchange relationships formed weaker ties. It is through these weaker ties that diverse networks could be built across chronic illness populations (Vassilev et al., 2013) and transplant recipient populations (Grumme & Gordon, 2016) resulting in improved illness management.

In developing the concept of reciprocating from Wainwright (1995) transplant trajectory further, more recent research has discovered the complex moral relationships transplant recipients have with their donor. Here, the 'gift of life' metaphor which has long been part of the transplantation rhetoric where organ donation is perceived and viewed as a gift (Fox & Swazey, 2002) has implications on reciprical networks. The application of the 'gift of life' metaphor has been used to demonstrate the success of transplantation and as a way of increasing donation rates. Yet, the discourses often fail to acknowledge the psychosocial complexities for transplant recipients moving through these discourses. O'Brien, Donaghue, Walker, and Wood (2014) noted that the notion of gift influenced reciprocity and a sense of indebtedness (Sharp, 2006; Sque & Payne, 1994), which could not be repaid in the case of deceased donation, often promoting the notion of 'pay it forward' through altruistic acts as a way of coping with the moral obligation of transplantation. One study worth noting at this stage, is that of Ummel and Achille (2016) which looked to understand the relationships between recipients and donors that were from genetic, emotional or casual relationships. The authors found that transplantation offered unique social contexts between dyad donor and recipient relationships which influenced the meaning of receiving a transplant. Here, the obligation to give back as a recipient was found to be more present with recipients who had received a donation from casual relationships compared to those receiving an organ from family relations. This was due to the existing social roles that family relations occupied which

involved ordinary kinship obligations in which transplantation could fulfil. Further, casual relationships did not accept forms of gratitude which made it difficult for recipients to make sense of receiving a transplant.

Expressing gratitude is one way in which recipients can manage the 'tyranny of the gift' (Fox & Swazey, 2002). Research has suggested that gratitude can be a useful response due to the multitude of ways it could enact responses beyond what would be possible at a transactional level (O'Brien et al., 2014). These findings are important to consider when attempting to understand self-management behaviours and specifically transplant recipients' engagement in exercise, sport, and Transplant Games events because recipients may even benefit from expressing gratitude from a health and wellbeing perspective. However, O'Brien et al. (2014) found that although gratitude produced positive emotional responses, it also exhibited various negative emotional responses including anxiety, guilt and obligation. A key finding was the theme *giving forward* which represented a way for transplant recipients to overcome reciprocity, managing the negative emotions associated, through giving forward and offering support to others (O'Brien et al., 2014). Participants achieved this through joining support groups with which they could assist others going through similar health concerns. This finding supports the earlier work of Wood, Maltby, Gillett, Linley, and Joseph (2008) who demonstrated that when positively perceived, gratitude increased social functioning.

Overall, gratitude has a profound impact on influencing social actions and these findings are important when attempting to understand transplant recipients' self-management behaviours and specifically engagement in sport and Transplant Games events. Participating in Transplant Games events may be a useful way of facilitating social networks, specifically weaker ties, navigating the illness trajectory, and reconstructing the future self.

2.4 Living with an organ transplant and the transformation of the 'self'

Beyond the medical challenges associated with self-management and living with a transplant, there are several emotional and social challenges which need consideration. Specifically, transplant recipients are faced with the continual shifting identity and social role responsibilities that flow between being healthy, becoming chronically ill, and receiving a transplant (Gallant, 2003). That is, individuals must handle their changing capabilities and learn to cope with the psychosocial impact this may have on them and their self-management.

Negotiating transitioning identity throughout chronic illness and transplantation is seemingly bound to the overall experiences of health and illness (Waldron, Malpus, Shearing, Sanchez, & Murray, 2017). As an embodied experience, chronic illness and transplantation could facilitate the self-discovery between the body and self and as such it would be useful to understand how the body and self may interact.

Previous research has used the concept of biographical disruption first considered by Bury (1982) to structure the illness experience (Charmaz, 1983, 1991; Engman, 2019; Williams., 2000). Bury (1982) describes biographical disruption as "attention to bodily states not usually brought into consciousness" where a "fundamental re-thinking of the persons biography and self-concept is involved" which requires a mobilisation of resources (Bury, 1982, p. 169). It is the disruption of everyday life narratives which individuals use to construct the trajectories of their future lives. Biographical disruption has been utilised across a variety of chronic illnesses including motor neuron disease (Locock, Ziebland, & Dumelow, 2009), stroke patients (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004), fibromyalgia (Asbring, 2001), breast cancer patients (Trusson, Pilnick, & Roy, 2016) and also transplant recipients (Engman, 2019).

Biographical disruption, loss of self and narrative reconstruction (Bury, 1982; Charmaz, 1983) are commonly associated with post-transplant life. Further, the transplant experience is accompanied with uncertainties such as organ rejection, regaining physical capabilities, and prolonged health (Martin, Stone, Scott, & Brashers, 2010). Taken together, research detailing the temporal aspects of chronic illness and transplantation provide a framework for describing the experience of living with an organ transplant and the transformation of the self. Engman (2019) conducted a study to understand the biographic disruption across a variety of transplant recipients accounting for various illness trajectories. Findings from the qualitative interviews revealed that chronic illness was not enough to produce biographic disruption. Instead, it was the effect of illness on the ability to carry out daily activities that influenced transplant recipients' illness experience. Engman (2019) stated that it was; "one's ability to enact the pre-conscious, spontaneous impulse to behave in a familiar environment, that accounts for the presence or absence of biographical disruption in experience" (Engman, 2019, p. 126). Here, it was the interruption to daily life that caused biographical disruption.

Despite the widespread application within research across chronic illnesses including transplantation, biographical disruption has received criticism for the disregard of demographic

characteristics such as age, gender, and social class. Williams (2000) argued that older individuals do not experience the same biographical disruptions with their identity as they had to come to terms with the trajectory of their lives over time which included lessening physical capabilities. The same could be said for childhood experiences of chronic illness where biographical disruption is less prominent due to the early integration of illness within the self-concept (Richardson, Ong, & Sim, 2006). Further, gender differences may influence experiences of biographical disruption as Wilson (2007) noted in a study on motherhood and HIV infection. This study found that the women maintained their identities as mothers despite the challenges of chronic illness and although disrupted, individuals were able to re-formulate their identities which considered biographical reinforcement. This study may have important implications for understanding how transplant recipients manage their roles and identity over time. Further, understanding how identity is situated within biographic disruption could help illuminate the biopsychosocial connection with chronic illness and transplantation.

It is the disruption at the level of identity which forms the biographic disruption which often encompasses the role as a sick person (Charmaz, 1983). The topic of identity has been the focus of much literature concerning patients' experiences of chronic illness for some time now. Charmaz (1983) found that individuals suffered a loss of self-identity because of chronic illness which included four sources: living a restricted life, social isolation, discrediting definitions of self, and becoming a burden. Chronically ill individuals sought social contact, but they found it increasingly difficult to maintain relationships as the demands of illness take over, thus leading to a restricted life and social isolation with an acute loss of social identity (Charmaz, 1983).

An important study to note concerning identity within the transplantation literature is the work of Svenaeus (2012) who looked at the identity changes across the experience of receiving an organ transplant. Here, the author considered identity as a multifaceted concept consisting of numerical identity and qualitative identity. Numerical identity was defined as 'identity over time' whereby a person would stay the same person as a process of change. Qualitative identity on the other hand referred to how two things could be qualitatively identical yet separate at the same time. Svenaeus (2012) used the definition of qualitative identity to describe how identity was integrated within the transplant experience and as such a transplant recipient was not seen as another person but instead, experiences a change in personal identity due to changes in self-traits because of transplantation. Svenaeus (2012) provided a phenomenological analysis of organ transplantation by firstly looking into the illness

experience within kidney disease patients. Findings indicated that kidney disease influences changes on the embodied and existential self-reflection level. Receiving a kidney transplant leads to existential reflection including feelings and thoughts around thankfulness and guilt with receiving an extended life. Overall, the study found that analysing the self and identity of transplant recipients required a social-narrative phenomenological approach of the experience of illness and transplantation rather than just assessing the physiological adaptations and new functions associated with the new embodiment.

Following on from the work of Charmaz (1983) and Svenaeus (2012) more recent research has determined the identity challenges transplant recipients face as they deal with chronic illness and move towards resuming normal functioning post-transplant. For example, Aujoulat et al. (2014) looked to understand factors that impact on the capacity of young liver transplant recipients to care for the self. The authors found that adolescents experienced challenges with integrating their identity and illness experience. Specifically, the psychological challenges were centred on building a sense of purpose and self-ownership and overcoming the trauma of survival. The transition experiences of these liver recipients towards integrating their illness within their sense of self and identity was dependant on the illness centrality which the authors defined as "the extent to which the illness experience plays a central or peripheral role in an individual's self-definition" (Aujoulat et al., 2014, p. 363). Further, the authors highlighted a growing body of literature evidencing how the centrality of illness could impact on self-care capabilities (Helgeson & Novak, 2007; Tilden, Charman, Sharples, & Fosbury, 2005). This body of work looked to establish a greater understanding of how chronic illness impacted on identity which influenced health and self-management outcomes. Here, the focus is on acknowledging the various identities such as that of an illness identity and integrating these identities to form a sense of self.

Aujoulat et al. (2014) suggested that this may be something which could be offered and implemented as part of psychosocial support within formal healthcare settings. The authors also note how alternative approaches to maintaining a continuous sense of self have been considered which has included the use of art therapy and narratives (Piana et al., 2010). More recent research has supported these claims through determining the role creativity plays in the growth following chronic illness which have implications for reconceptualising a sense of self and identity (Tolleson & Zeligman, 2019). These findings are important in the context of this thesis as sport and participating in Transplant Games events may also offer a creative

alternative psychosocial development tool which could impact on recipients' sense of self and establish an identity away from chronic illness.

Similarly, Ouellette, Achille, and Pâquet (2009) conducted a phenomenological study considering patient experiences of kidney graft failure. Results indicated five key themes: *life disruption, suffering, meaning making, resistance/acceptance* and *social comparison*. In agreement with Aujoulat et al. (2014), the authors found within their *resistance/acceptance* theme that participants were challenged with integrating their illness within the reality of their lives as they often experienced a duality between accepting illness and resisting it. Here, the integration of illness within daily life and definitions of the self were difficult for some participants to comprehend. Ouellette et al. (2009) support the earlier work of Parkes (1971) and utilised the concept of 'psychosocial transition' which describes how transition is influenced by major life events such as chronic illness or transplantation which constantly changes with the trajectory of illness. Further, illness threatens individuals 'assumptive world' which promotes change as individuals adapt to a new way of being, leaving behind deeply rooted views of the world. For transplant recipients, identity is constantly negotiated as a duality between sickness and health, self and illness and life and death. Sontag (1978, p. 3) stated: "Everyone holds dual citizenship in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place". For transplant recipients, their illness experience is less dichotomous, positioned somewhere between these binaries.

To understand transplant recipients' illness experience further, and in answering Bogue Kerr et al. (2018) call to move beyond the language of 'transition', I place an emphasis on the concept of liminality which extends and is not limited to transitions but explains the complex journey of transplant recipients' negotiation of space during and through a rite of passage. Crowley-Matoka (2005, p. 827) described liminality as "a state through which individuals must pass as they exit the normal structure of society in order to re-enter it again in a new social role". Previous research has stated that temporary liminality is experienced post-transplantation and recipients expect to be between the sick role and the healthy role for a limited period of time whilst they protect their suppressed immune systems (Gennep, 1960; Van Gennep, 2019). Yet, Crowley-Matoka (2005) found that post-transplantation, recipients were unsure of when illness was to end, and instead it seemed as though this was much more open-ended. This uncertainty delayed the development of their social identity into a completely new transformed self and, instead, it blurred the lines between the roles and identity of the individual. The

authors interviewed 50 transplant patients to elicit illness narratives and found recipients were in persistent liminality which was separated into three key elements including health, productivity, and re-productivity. The study found that transplantation did not lead to the regaining of pre-illness self which required acute tolerance of immunosuppressive treatment to avoid rejection and various side effects related to immunosuppressive medication (such as heart disease). The authors stated that when recipients do end the liminality period, they found returning to normal life was not so straight forward. Overall, the study found that recipients could never restore the healthy self but instead, remaining "betwixt" ill and healthy (Crowley-Matoka, 2005). Canguilhem (1966) termed this an 'alternative normality' after transplantation whereby the immunosuppressive medication and associated side effects reflected transplant recipients' liminal existence.

Similarly, Bogue Kerr et al. (2018) took a phenomenological approach to exploring the experiences of five young adults' kidney transplant recipients. Analysis revealed these experiences were paradoxical in nature in which liminality was identified along with the concept of 'rites of passage' as a way of explaining these experiences. In extending the work of Crowley-Matoka (2005) the authors conceptualised how transplant recipients navigated the liminal space through their unique illness experiences within the term 'transliminal self'. The authors stated that: "the transliminal self never completely emerges from its rites of passage and is never completely healed. Recipients exist in a liminal space and are deeply aware of their mortality" (Bogue Kerr et al., 2018, p. 568). Furthermore, the everyday experiences of transplant recipients are influenced by the ongoing physical effects of medication which in turn impact on the psychological aspects. Bogue Kerr et al. (2018) findings can be determined in relation to the stages of liminality, separation, transition, and integration. During the separation phase a person prepares for changes and is ready to acquire a new social position. During the transition phase a person is on the threshold of something new, filled with ambiguity. The person will transform into a new social status and resume the status of a healthy person. In transplantation the transition phase is understood as a recovery stage post-transplant as the recipient begins to experience life with a new organ. Overall, transliminality involves bargaining with an identity that is continuously changing with the demands of chronic illness which evolves through medical intervention and through engagement with health professionals. Here, the physiological changes influence the formulation and conceptualisation of a transplant recipient identity.

Cormier et al. (2017) conducted a study to highlight the ways in which organ recipients redefined their identity following the physiological challenges faced because of illness. Through a sociological lens looking at the social identity of the organ recipients, the authors determined how this changed across the continuum of waiting for an organ transplant to receiving one. Analysis identified four main themes including *journey into liminality, waiting continuum, obstacles and false alarms*, and *new transplanted self*. Of specific interest here is the finding *new transplanted self* which concerns the fluidity of stable identities post-transplantation contributing to the ambiguity surrounding individuals' biophysical selves. The authors suggested that these identities are best placed along a continuum from 'better than well' to 'return to normal' to 'embracing the abnormal'.

Overall, the transplanted self reflects transplant recipients' navigation across the biomedically engineered road, and that the new self emerges from how individuals respond to the social risks, physiological and pre-existing social context. Cormier et al. (2017, p. 1499) stated:

> The transplanted self is an identity process shaped by engagement in both the medical and social worlds and entails a range of cognitive strategies and subjective interpretations of the biophysical and identity transformations recipients' experience.

This study highlights that the physiological changes can only partially explain the newly transplanted identity. It is the psychological and social experiences an individual engages in that contributes to the post-transplant identity. Cormier et al. (2017) recommend that future research should seek to develop this further by exploring the narratives of organ recipients over time following their transplantation journey from a sociological standpoint with a focus on the self-management and risk of organ failure as key areas of future research.

Previous research has attempted to draw together the social experiences in determining transplant recipients' identity. For example, Forsberg, Bäckman, and Möller (2000) found that transplant recipients were concerned with recapturing the body post-transplant and that meeting other recipients allowed individuals to share experiences of survivorship unique to being a transplant recipient. Here, social support and meeting other recipients promoted ways of dealing with identity disruption and loss which allowed recipients the opportunity to position their self towards others as a survivor and away from being unique. Similarly, Shildrick, McKeever, Abbey, Poole, and Ross (2009) conducted a study looking at the dimensions of heart transplantation acknowledging the changes experienced to embodiment and personal identity. The authors found that, following transplantation, individuals may experience

disruption in their sense of embodiment and self and may experience bonds with their donors. In support of discovering the social experiences and the impact on transplant recipients' identity, Tong, Morton, Howard, McTaggart, and Craig (2011) determined the facilitators and barriers to achieving normality after kidney transplantation among adolescents. The facilitators concerned developing identity, peer acceptance, routine medications, freedom and energy, and support structures. The barriers to normality were identity crisis, peer rejection, poor medical adherence, lifestyle limitations, and fear and uncertainty. The authors recommended that transplant recipients should seek contact with other recipients to share feelings, personal questions, and coping strategies. Furthermore, the authors suggest support could be sought through kidney camps, support groups, online communities, and the Transplant Games.

Transliminality may impact on self-management and social roles within individuals' personal networks and therefore may become a social process that needs further understanding. As transliminality and the challenges with identity are part of transplant recipients' self-management experience, an understanding of how individuals navigate within social networks across the illness trajectory and their assigned roles may help in understanding the wider social context and the role of others in self-management. Furthermore, it is the biographic disruption which influences network dynamics and roles within a network (Perry & Pescosolido, 2012; Vassilev et al., 2013). Overall, the trajectories of chronic illness and transplantation inevitably influence the personal communities of individuals adapting to changes to their health over time which may impact on the availability of support within individuals networks (Rogers et al., 2014). As such, these findings are important to consider when attempting to understand transplant recipients' engagement in the wider social context.

2.5 Negotiating chronic illness through sport, exercise, and physical activity

Consensus exists about the health benefits of sports and exercise activity across medical populations and chronic illnesses. Sport has been used as a tool to help a variety of different populations including; disabled persons (Smith, 2013), trauma victims (Ravizza, 2010), individuals with intellectual and other developmental disabilities (Glidden, Bamberger, Draheim, & Kersh, 2011) as well as chronically ill populations (Fuchs, Perrin, & Ohl, 2014; Le Hénaff & Héas, 2020). Qualitative research has been used to better understand people living with chronic illness and their experiences of taking part in sport and exercise for people with

arthritis (Hunt & Papathomas, 2020), multiple sclerosis (Richardson, Barstow, & Motl, 2019), asthma (Allen-Collinson & Owton, 2014; Owton & Allen-Collinson, 2016) and heart disease (Meredith, Wagstaff, & Dicks, 2019; Moola, Faulkner, White, & Kirsh, 2015). Being active has been recommended as part of maintaining a healthy lifestyle, as a way of self-managing chronic illness (Williams & Stevens, 2013). Research with chronically ill populations has also focused on a variety of health and psychosocial outcomes including psychological wellbeing, quality of life, and social integration detailing how sport has been used as a tool to better psychosocial outcomes. Blauwet and Willick (2012, p. 851), for example, stated:

> Participation in sports, when used as a tool to promote health, quality of life, and social integration, is a universal cultural construct that crosses divisions of disability, age, gender, socioeconomic status, and ethnicity.

This has contributed to a wealth of literature assessing the benefits of sport, whether as a coping mechanism to overcome chronic illness or as an intervention to improve quality of life, mental health, or social integration skills (Blauwet & Willick, 2012). Despite this, there is a paucity of research which has assessed the impact of sports participation across the trajectory of chronic illness. Understanding the illness journey and at what stage an individual may require certain types of support for managing illness could be useful when determining at what stage sport is introduced. Although, it is important to note that sport may not be for everyone and therefore the benefits may not be derived in the same way. Further, illness may limit individuals' ability to enact sport or engage in sport in a meaningful way which promotes benefits.

An important point for consideration in this section is, therefore, the illness trajectory and its impact on sport participation. Further, as sport is used to reconstruct the self and identity it may be useful to understand how the illness trajectory may influence sport participation and vice versa. One way of restructuring the future self may be through sports participation as those who are chronically ill may use sport to position and come to terms with their body failure as well as construct an identity away from illness. Research has looked at how sport participation plays a role in the life course and illness trajectory of individuals with chronic illness. For example, Fuchs et al. (2014) conducted a qualitative survey combining observations and interviews with sports people with cystic fibrosis to understand their commitment to sport and to grasp its effects across the illness trajectory. Commitment to sport enabled individuals to maintain an 'enchantment to their physical capabilities' and former identities as a way of taking control of their bodies. However, sporting commitment went through a process of adaptation with illness. Thus, individuals adjusted their sport commitment as a way of coping with the

physical, psychological, and social difficulties associated with their illness over time. As the disease becomes more present, the body fails to stand up to the illness trajectory, and therefore the illness imposes the adaptations for the individual to continue sport participation. Fuchs et al. (2014, p. 203) stated:

> While a commitment to physical and sporting activities can be a resource at certain moments in the trajectory of the disease, it can also be a source of malaise. In seeking to conform to the normativity of the sporting body, the commitment accentuates the sufferings linked to the impossibility of avoiding the crippling effects of the disease.

The authors found that sport became a disease management activity which allowed individuals to find meaning in their lives and developing a positive self-perception through taking control of their bodies (Fuchs et al., 2014). The authors' findings also included the resumption of commitment to sport and the meanings individuals who received a transplant attached to taking part in sport. Here, individuals who could be effective in sport, targeting beating records, could manage achieving something which enabled internal and external identity as a sports person. Furthermore, the motivations attached to taking part in sport were attributed to raising awareness for organ donation and to provide support to others. This may support the evidence that individuals were in the reciprocating stage of the transplant trajectory (Wainwright, 1995) enacted through taking part in sport. Further, sport at this stage offered a way to fulfilling the need to give back and as a way of managing the indebtedness and guilt experienced (Sharp, 2006; Sque & Payne, 1994). Fuchs et al. (2014) discussed how commitment to sport changed dependent on the illness trajectory of individuals with cystic fibrosis. The relatedness of disease may implicate the meanings attached to sport as individuals move towards adapting as they cope with the physical, psychological, and social difficulties. Sport becomes a way in which individuals can control their illness trajectory. However, whilst sport may benefit as a resource for managing illness, sport also illuminated health decline and, in some cases, accentuated suffering. That is, sport highlighted the ongoing limitations individuals faced through the assignment of disease.

Similarly, Le Hénaff and Héas (2020) assessed the impact of physical and leisure activity with a chronically ill population of persons with pemphigus (a dermatological disorder). The authors used a biographical approach, like Fuchs et al. (2014), to understand how leisure activity could be used as a potential resource for ill recipients as well as an indicator of illness disruption. The authors identified four types of engagement in leisure activities which included disengagement connected with biographical disruption, adapted engagement consisting of less high-risk activity engagement in medicalised normalisation and salutary

engagement. Le Hénaff and Héas (2020) noted that disengagement of activity assumed biographical disruption as the resignation of leisure activity confirms the acceptance of the illness. That is, illness no longer provides the motive to engage in leisure or physical activity. This study contributes to understanding biographical disruption through taking part in leisure activities where illness offered an opportunity to reconfigure the self, individual identity, social relationships as well as reconstruct leisure pursuits as a way of "resetting normality" (Sanderson, Calnan, Morris, Richards, & Hewlett, 2011, p. 630).

Specific to transplant recipients, a recent study by Bobrowski (2020) looked to understand how sport participation for paediatric organ recipients post-transplantation could offer a way of transitioning to normal life. That is, sport could be a way of negotiating the trajectory of the transplant and chronic illness. The authors found that sport could improve physical, psychological, and social outcomes and as such the authors recommended that sport is prioritised with these populations. The authors agree with the earlier work of Fuchs et al. (2014) and Le Hénaff and Héas (2020) in the use of sport for negotiating chronic illness and transplant trajectories. Whilst these studies have highlighted the benefits of sport participation for managing illness and transplantation regarding the illness trajectory, it is important to acknowledge research outlining how sport could also impact negatively on the assignment of illness, acting as an opportunity to fulfil unhealthy obligations, and cause more distress dependent on how individuals move through illness.

Overall, these findings are important to consider when attempting to comprehend transplant recipients' engagement in Transplant Games events because they offer an understanding of the complexities associated with enacting sport for chronically ill populations which can be readily applied to transplant recipients. Here, sport research has contributed to the literature addressing the illness trajectory and implications from a psychosocial perspective in offering an alternative approach to managing these outcomes. That is, research has shown that taking part in sport has promoted the application of innovative healthcare plans towards prescribed physical activity and sport as part of self-management practices. Furthermore, research into sport and chronic illness has exhibited interest in the positive impact of sport as a leisure activity which can impact on sense of purpose (Nimrod, Kleiber, & Berdychevsky, 2012), positive self-image (Fuchs et al. 2014) and stress reduction (Gillett, Cain, & Pawluch, 2002). Transplant recipients have similar challenges as the above mentioned chronically ill populations in that they are tasked with negotiating the illness trajectory and ongoing

fluctuating health. As such, transplant recipients may turn to sport and physical activity as a way of demonstrating good health, controlling their illness trajectory and as a way of giving something back. However, more research is needed to further determine the psychosocial outcomes of participating in sports such as Transplant Games events for transplant recipients and research is needed to address the impact participation may have on recipients' trajectory of illness, identity, and illness self-management networks important for post-transplant outcomes. Understanding the way Transplant Games events may facilitate psychosocial outcomes could prove a fruitful area for progressing the application of sport across other chronically ill populations. Specifically, no research that I am currently aware of has looked to understand participating in Transplant Games events as a way of negotiating the illness trajectory which may help broaden an understanding of how illness impacts sport participation.

2.6 The role of the Transplant Games as a psychosocial self-management tool

The management of transplantation consolidates commitment to sport, as competitions such as Transplant Games events embody the health practices, physical activity levels and psychosocial support necessary for better self-management outcomes. There is a growing body of research discovering transplant recipients wide ranging experiences of competing in Transplant Games events including physiological, psychological, and social responses. Here, I will outline the extent of existing research that has assessed the impact of Transplant Games events from a psychosocial perspective. Furthermore, I will highlight research which has recognised the role of Transplant Games events in facilitating transplant recipients' social networks and weaker ties to draw links between the scholarship outlining the role of informal networks across chronically ill populations (Allen et al., 2016, 2020; Vassilev et al., 2014).

There are numerous studies assessing the impact of Transplant Games events on transplant recipients' quality of life (McGee & Horgan, 1996; Roi et al., 2014). An early study by McGee and Horgan (1996) assessed 12 cardiac transplant patients participating in Transplant Games events and found no change in health-related quality of life over time. However, the authors found that for most cardiac transplant recipients, they reported little difficulty with health-related quality of life. Despite this, the authors called for more research on cardiac transplant patients to understand the factors which influence health-related and general quality of life further. These claims have been challenged in more recent literature

assessing recipients' quality of life. Roi et al. (2014) formed the 'Transplant…and now Sport Project' which was shaped around the idea of physical activity as a non-pharmacological therapy initially for solid organ transplant recipients who were participating in the Italian National Championships (alpine skiing, track and field, cycling, swimming, volleyball, and trekking). The 'Transplant...and now Sport Project' involved the cooperation of transplant medical doctors, physicians, and exercise specialists. The authors found that those involved in sporting competition were able to maintain a healthy lifestyle (Roi et al., 2010) and reported improvement in health-related quality of life (Macdonald, Kirkman, & Jibani, 2009; Mosconi. et al., 2011; Painter & Marcus, 2013). These findings support the notion that sport activity improves health-related quality of life which somewhat disagrees with McGee and Horgan's (1996) earlier findings.

Although there exists a paucity of research on the psychosocial impact of sports activity for transplant recipients (Painter & Marcus, 2013; Roi et al., 2010), more recent research has attempted to answer these calls and close this gap (Cicognani et al., 2015; Mazzoni et al., 2014). For example, Mazzoni et al. (2014) found kidney recipients who engaged in sports activity were able to achieve a similar quality of life to that of the active general population and sport reduced the negative consequences of transplantation. The authors found that the benefits of sport activity to move beyond physical health and extended support for the psychosocial components of an improved quality of life which included social functioning. The findings also determined the link between the biological factors and the psychosocial components and how they interact which was explained as an 'adaptation process' which transplant recipients transition through once they have received their newly transplanted organ. This can be likened to the early stages within Wainwright (1995) five-stage trajectory model. This discovery process allows for greater appreciation as recipients reset their expectations which in turn improved their health-related quality of life.

Following the trajectory idea, previous research that has reported general improvements in quality of life may have been experienced as a direct result of receiving a lifesaving transplant and moving from an ill self to a healthier stable self. However, research assessing the impact of sport has been limited when considering the shifting liminal state (Crowley-Matoka, 2005) experienced by transplant recipients which could have a bearing on their identities and overall psychosocial outcomes. As Fuchs et al. (2014) stated; "the interests associated with the sporting commitment constantly evolve in the dissimulation/acceptance of the illness trajectory" (Fuchs et al., 2014, p. 191). Here, the transliminal self may influence or

be impacted by participation in sport. Furthermore, understanding the links between the transliminal self and sport participation may be a useful way of addressing the calls to examine the biologic and psychosocial interaction. Moreover, understanding the longevity of the illness trajectory and how that impacts on sport participation may be valuable for practitioners and medical staff when determining the timing of sport or physical activity interventions or when to promote sport as a tool to improve health and self-management outcomes. It may also provide evidence to support the necessary psychosocial components that should be embedded in these types of interventions as a major facilitator and motivating factor. Further, psychosocial support may also help with the personal development of recipients' identities post-transplantation.

The evidence presented thus far supports the idea that sport activity positively impacts on health-related quality of life including social functioning, general health perception and mental health. Yet, research has called for more research to address the interaction between the biologic and psychosocial processes and how sports activity could impact on post-transplantation self-management outcomes (Mazzoni et al., 2014; Cicognani et al., 2015). Mazzoni et al. (2014, p. 2234) stated:

> More research is needed to clarify how psychologic and psychosocial processes interact with biologic factors in explaining the experience of these patients and the role of sports in sustaining recovery processes as well as maintenance of a healthy condition after transplantation.

The extent of research on the World Transplant Games has been focused on the medical and physical benefits of participation (Deliva et al., 2014). Despite this, some research has focused on the psychological outcomes of transplant recipients taking part in the Games (Atamañuk et al., 2017; Johnson et al., 2013; Wray & Lunnon-Wood, 2008). Johnson et al. (2013) made an important contribution to the literature and has set the precedence for more focus on the psychosocial demands transplant recipients are presented with and overcome through participating in the Transplant Games. Johnson et al (2013) looked at 253 participants from the World Transplant Games events and addressed five research questions on health, satisfaction with sports participation, personal competence, health as a benefit of sporting participation and impaired health as a cost of sports participation. Findings revealed that clinical psychological factors including personal competence, enjoyment and worth were critical motivating factors influencing participation within the Games. The practical significance of this study was twofold. Firstly, it contributes to the growing evidence on the benefits of taking part in Transplant Games events and secondly, the study offers an

explanation as to why recipients take part in Transplant Games events. The authors found that most participants taking part in Transplant Games events had been previously active pre-transplant which led to their initial involvement. Here, previous sporting history may be a precursor for the continuation of sport post-transplant. This may have important implications when promoting sport across transplant populations that have not been previously active as some may not seek participation in sport as a way promoting a healthy lifestyle. Instead, transplant recipients may not engage in sport and Transplant Games events altogether and may seek other forms of physical activity or exercise.

Atamañuk et al. (2017) examined how exercise affects the wellbeing of organ transplant recipients taking part in the 2012 Latin American Transplant Games. One of their study objectives was to understand the role of the physicians in promoting the Games. They found that the impact of the activity on self-reported conditions was 'dose-dependent' although 95% of participants reported their global health condition as good (30.6%), very good (43.95%), or excellent (19.75%). Future suggestions point towards diverse and intense exercise to improve self-reported health outcomes. The authors also call for a greater involvement from physicians when promoting the Games because they found that most transplant recipients learnt about the Games from other organ transplant recipients, relatives, or transplant foundations. Overall, Atamañuk et al. (2017) support the earlier work by Johnson et al. (2013) documenting the self-reported psychological health benefits and wellbeing associated with participation in the World Transplant Games events.

Both Atamañuk et al. (2017) and Johnson et al. (2013) emphasise the importance of the physicians' role in promoting participation in Transplant Games events which brings into question the clinician-patient partnership. The notion of moving away from the dependency of healthcare providers towards self-managing one's own condition may also reflect the lack of emphasis from medical practitioners in promoting Transplant Games events. Instead, transplant recipients become experts of managing their illness and therefore know whether to pursue an active lifestyle. However, future research may look to consider how transplant recipients engage in Transplant Games events and how this may be influenced by their relationships with sport and their existing networks, including relationships with medical practitioners.

Having reviewed the literature on transplant recipients' participation in Transplant Games events, the extent of research has demonstrated the psychological benefits, yet it is apparent that clear gaps exist when determining the social outcomes. One question remaining from this review is whether the impact sport on transplant recipients' quality of life is solely

due to the bio-psychological outcomes experienced from taking part in this activity or perhaps the wider social context has an important role to play in these outcomes. This provides an opportunity to explore how the social network literature may help further evaluate the impact of participating in Transplant Games events from a sociological standpoint. As Slapak, discussing the social benefits of participating in the Transplant Games, stated:

> There is the addition of the companionship of peers, the confidence of seeing and meeting hundreds of persons who have triumphed over similar adversity and the embracing warmth of belonging to a worldwide club a truly remarkable benefit becomes obvious to all those present….The return of an individual after a successful organ transplant demands social integration to correspond with full physical rehabilitation (Slapak, 2005, p. 63).

Despite this, scant research has been able to determine to what extent the wider social context plays an important role in the health and overall self-management of transplant recipients and how participating in Transplant Games events may facilitate social interaction and develop informal networks of support. The Cho et al. (2017) review study agreed with the work of Slapak (2005) in that the rehabilitation of recipients through sport and physical activity is "essential to return to normal social life" (Cho et al., 2017, p. 6). The authors acknowledged how Transplant Games events were developed not only to promote organ donation but for recipients to improve and develop friendships. According to Cho et al. (2017), an early return to normal social life could reduce the burden on health professionals which is consistent with the rhetoric within the self-management and chronic illness literature that determined the importance of informal sources of support (i.e. family, friends) in providing types of work (Vassilev et al., 2013; Vassilev et al., 2014) and the role weak ties may play in better self-management outcomes (Rogers et al., 2014). Moreover, participating in Transplant Games events may facilitate individuals' social networks which could be important when considering the wider social implications. However, the Cho et al. (2017) study is limited in its applicability and contribution to the literature given its status as a review paper. Further, the links with the wider chronic illness and self-management literature can only partially be made, given the limitations of this study. Nonetheless, this paves the way for quality rigorous research to establish these links further.

2.7 Summary

Within this chapter I have reviewed previous research which has emphasised the individual level focus of self-management interventions and programmes. Further, I reviewed literature which has placed importance on the need to involve the wider application of the social context. This included the role of others and informal social networks in shaping self-management outcomes and practices. Furthermore, through discovering the challenges individuals face when managing chronic illness and transplantation, this chapter has demonstrated the impact of the biographical self and identity which could be defined through relational and social aspects. Moreover, having reviewed the literature, several key insights into the self-management of transplant recipients has been unveiled through the lens of sport. Previous literature has highlighted how sport may offer links to individual challenges and self-management outcomes as a way of restructuring the self and negotiating transliminality. Previous research has also illuminated the potential impact Transplant Games events may have as a psychosocial tool with useful benefits.

Yet, the extant of literature review within this chapter has revealed several gaps. Firstly, there is a paucity of research addressing the psychosocial outcomes of participating in Transplant Games events for transplant recipients' self-management. Secondly, no studies to my knowledge have addressed the impact participation in Transplant Games events may have on transplant recipients' illness self-management networks. Further, research has not yet considered the impact of recipients' illness self-management networks across their illness trajectory which may influence self-management outcomes as well as their continued participation in sport over time.

CHAPTER 3: METHODOLOGY AND METHODS

3.1 Introduction

This chapter outlines and justifies the methodological approach and methods used within the study. First, I will provide a justification for critical realism as the philosophical approach to this study. In addition, I will outline the qualitative social network approach situated within a longitudinal design, implemented to gain a multi-layered perspective of transplant recipients' social networks over time. Second, this chapter provides a detailed outline of the methods used, including the sampling strategy, data collection process and the analysis of the data which includes the thematic analysis of the interview transcripts and visual network analysis of personal network diagrams. I will then outline the final part of the analysis which consists of a longitudinal component which builds on the analysis to represent change over time. Furthermore, this chapter will discuss the validity and quality of the research and will outline the ethical issues and challenges involved in this study. Here, I will outline the implications in conducting longitudinal research and managing ongoing relationships between the researcher and participant. Finally, I will highlight the implications associated with the methodology used whilst looking to address these concerns through the justifications and application of methodological rigour.

3.2 Methodological approach

Philosophy is an important part of research methodology which concerns the beliefs and assumptions about the development of knowledge which may help in refining and clarifying the appropriateness of research methods (McNamee, 2004). Research philosophy is classified as ontology – concerning reality, and epistemology – concerning knowledge. Within the field of sport, exercise and health, positivist and quantitative approaches to research has been dominant. However, qualitative researchers have come to reject this position and have drawn on different philosophies moving away from positivist approaches. In more recent years, qualitative researchers have favoured constructivist-interpretivist paradigmatic approaches which reject positivist assumptions by taking reality to be multiple, subjective, and socially constructed (Wiltshire, 2018). In aiming to offer rich nuanced and complex experiences of different realities, it detaches social ontology in search of complex interpretations of phenomena at the expense of not fully 'exploring how social phenomena came to be' (Wiltshire, 2018, p. 530). Wiltshire (2018) believes that these approaches have gone too far

and has argued for a middle ground. Having identified the concerns within the literature of an individualistic focus on self-management, a critical realist approach could help in understanding the mechanisms of the social context and offer this middle ground. Thus, supporting a focus away from individualistic outcomes. Critical realism will be discussed in terms of the importance attributed to social structures and relations with a view of supporting the research approach with which this thesis is situated.

Critical realism offers an alternative viewpoint to variations of positivism and constructivism and has informed previous health (Clark., MacIntyre, & Cruickshank, 2007; Harwood & Clark, 2012) and sport (Figgins, Smith, Sellars, Greenlees, & Knight, 2016; Ronkainen, Tikkanen, Littlewood, & Nesti, 2015) research. Critical realism, as developed by Roy Bhaskar (Bhaskar, 1975, 1978) begins with the rejection of positivism such as cause and effect relationships which tend to identify correlations to understand social phenomena. In contrast, critical realism describes nature and society as operating in open systems, whereby causation in multiply determined. As such, positivist approaches have adopted more empirical frameworks which fundamentally disagrees with critical realism which is more explanatory.

Critical realism also explicitly rejects interpretivist approaches. Interpretivists believe that reality is socially constructed where an objective reality cannot exist (Bhaskar & Danermark, 2006). Critical realism takes the ontological stance (beliefs about the nature of the world) that the social world exists independent of our conception and understanding of it and the epistemological position (how we come to know the world) that knowledge is socially negotiated, shaped by the researchers' assumptions. Its relativist epistemology assumes a 'clearer position in terms of the context and direction of explanatory research in order to avoid the partiality of other positions' (Bhaskar & Danermark, 2006). The foci for critical realism, therefore, is ontology and explicating the nature of reality. Ontological realism concerns the *real, actual,* and *empirical* dimensions. Social phenomena are real where something caused it to exist whereby its foundations are situated between the real world and observable world. The 'real' exists independently of human perception of it, which cannot be observed. The empirical is the domain of actual experiences and the actual refers to events which happen without our conception, which is independent of whether its observed or not (Bhaskar 1978).

Critical realism emphasises the importance of social structures and social relations, which strikes an uncompromising similarity with the underpinnings of social network research (Buch-Hansen, 2014). Donati (2010, p. 98), a critical realist, notes, "social reality is social

relationality… society does not have or include social relations but consists of social relations". Here, the social relation is a dynamic process of elaborated structures. It is between timepoints that social structures change through interactions. We can understand that over time social relations interact, this interaction changes the structure of relations (Donati, 2010). Donati (2010) explains that for social intervention research to be effective then it needs to focus on change of the social context not the individual. If social research attempts to change the individual they will fail completely because relations are not the product of the individuals, they have a different order of reality. It is about understanding the ontology of social relationships before I begin to study them and it is through the lens of critical realism that I can begin to place social relations as real existence despite not being observable at an individual level. Furthermore, social relations are important to regulate situations of change as Donati (2010, p. 97) stated that it "is the reality of 'social facts (or phenomena)', meant as relational products generated by unceasing cycles entailing individuals' social agency conditioned from the start by the structures present then, through an interaction between actors, to the development of new structural, cultural and agential forms". It would therefore be paramount to this thesis to discuss how critical realism and social networks can be brought together.

Critical realism represents an opportunity to challenge and develop some of the dominant assumptions in social network research. Much social network research embraces a positivist standpoint which tends to manifest around network generalisations (Buch-Hansen, 2014). In that sense, these approaches focus on descriptive statistics and mathematical modelling to describe the structure of social relationships. The early social network research developments were attributable to the work of Moreno (1953), who drew upon and was influenced by the work of Comte. Many have attributed the so-called positivistic characteristics of social science to Comte (Freeman, 2004). It is, therefore, no surprise that much social network research aligns closely with positivist tendencies (Freeman, 2004). Furthermore, as positivism was established long before social network research, it is known that this would have influenced its development even without the work of Moreno (Buch-Hansen, 2014). To fully understand how critical realism could be applied to social network research, or how social networks can be 'detached' from positivistic approaches we must establish what is known about the theoretical positioning of social network research.

There are various ways in which positivism can be drawn out of social network research. Firstly, positivism draws on reductionist tendencies which is evident in how social network analysts combine the use of theory and models to support its application. For example,

Knoke (1990) and Emirbayer and Goodwin (1994) combined rational choice theory with social network analysis (SNA). It is testing hypothesis through theory that forms this deductivist stance (Marin & Wellman, 2011). Second, SNA researchers use mathematical models in order to describe and explain social structures (Bellotti, 2014; Buch-Hansen, 2014). This relies heavily on a reductionist ideal where these mathematical approaches limit other contextual outcomes. Thirdly, SNA is focused on the universals of social structures and behaviours. Like positivist approaches, SNA is concerned with how principles could be applied across groups and organisations as individual network members are grouped together to form these universals. Again, this approach does not align with the core principles of critical realism as universals limit society as an open system.

Another way in which positivist tendencies can be seen in SNA is through attempting to predict future interactions between social phenomena situated within a network. The work of Liben-Nowell and Kleinberg (2007) provides an example of how network modelling looks to achieve these predictions through the link-prediction problem, analysing the proximity of nodes within networks. The authors determine the evolution of social networks by predicting the movement of its snapshot in time, extracted through network typologies. This idea is fundamentally positivist in its approach which limits the openness of social systems (Bhaskar, 1978; Buch-Hansen, 2014; Sayer, 2000). Therefore, examining and explaining change in social phenomena through past and present interactions may be a way of understanding the evolution of social networks accounting for the openness of these systems.

According to Buch-Hansen "SNA techniques have the potential to be a valuable instrument that is currently missing from the critical realist toolbox" (Buch-Hansen, 2014, p. 322). Placing SNA within a critical realist ontology and epistemology may be a stronger position then its current place within positivist grounds (Buch-Hansen, 2014). Despite the largely positivist stance within research and the various approaches to network science researchers have supported the application of SNA across other theoretical and methodological remits (Bellotti, 2014; Borgatti, Everett, & Johnson, 2018; Borgatti, Mehra, Brass, & Labianca, 2009; Brandes, Freeman, & Wagner, 2013). Bellotti (2014) stated:

> Narrative accounts are claimed to provide an understanding of the subjective perceptions of causal mechanisms, directing the process of research toward plausible explanations because social reality is pre-interpreted by social actors, theories of social phenomena are necessarily concept dependent.

Buch-Hansen (2014) questioned how SNA could be 'detached' from positivist social science and 'attached' to critical realism. As SNA approaches are continuously being developed perhaps it is more a case of aligning the data collection procedures towards an approach that fits the ontology and epistemology of critical realism. Within this thesis, I will use Buch-Hansen (2014) conceptualisations on how critical realism can be used to frame the social network approach important to the aims of this study.

So far, this section has detailed and provided support for a critical realist approach to social network research, outlining the traditional positivistic tendencies which have led to an overwhelming quantitative focus within the research to date. Within this thesis, I hope to contribute to the gap of alternative approaches using a qualitative longitudinal social network approach. In doing so, I will illuminate a novel approach to qualitative social network analysis and through a critical lens, I will detail and develop a foundation for ongoing discussions around the applicability of qualitative social network approaches. Overall, critical realism shares with network science some core elements, which reinforces its application with a qualitative methodology.

3.2.1 Qualitative longitudinal social network research approach

A longitudinal qualitative social network design was deemed to be most appropriate. As the research approach consists of several elements, each requires its own explanation and justification. Firstly, the overarching qualitative approach aims to understand social phenomena through revealing subjective meanings from the individuals perspective (Green & Thorogood, 2018). Further, it was the study of complex multidimensional phenomena (Curry, Shield, & Wetle, 2006) and exploring mechanisms as they unfold over time (Hollstein, 2011) that fit within the research questions of this thesis. Furthermore, several methods are used for the collection and analysis of qualitative data which is situated within various theoretical assumptions (Hollstein, 2011). Qualitative approaches offer the opportunity to interact with individuals who want to share, describe, and give context to their story. In this way, qualitative approaches offer the opportunity to emphasise meaning making and are open procedures. Within this study, I am concerned with answering different research questions and a qualitative approach helps to address some of these questions. Specifically, I am interested in capturing transplant recipients' experiences of their illness self-management networks. Therefore, a

qualitative approach would be best suited to obtain the meaning and context attached to these experiences.

A longitudinal design was utilised to explore changes over time. Thomson, Henderson, and Holland (2003, p. 185) stated that longitudinal qualitative research is a "deliberate way in which temporality is designed into the research process making change a central focus of analytic attention". A longitudinal approach offers the opportunity to understand causality of social, cultural and contextual processes (Thomson et al., 2003; Thomson & McLeod, 2015) and how individuals respond to change and their unfolding events over time (Bryman, 2016). Lewis (2007) identified four different types of change within qualitative longitudinal research which researchers should be aware of and should make sense of their different meanings. First is 'narrative change', which refers to the individuals unfolding change in stories, which does not assume a chronological order as narratives are not always clearly told in a linear way. In this way, participants may forget things or mention stories as they become relevant over the time course of a longitudinal study. Second is the 'reinterpretation by the participant', retelling the stories of experiences which are difficult to interpret as the researcher. Third is the 'researcher's interpretation', over time as researchers we learn and gain a better picture of a participant or a different understanding of their experiences. Fourth, Lewis (2007) suggests is 'no change', which may reflect stability or consistency in the story or that development has not occurred. Lewis (2007) draws distinctions between these four types of change to highlight the considerations and possible implications when analysing and interpreting longitudinal qualitative data. I will use these types of change to help guide the longitudinal design and analysis of this study. In doing so, I hope to provide clarity in how the experiences of transplant recipients competing in Transplant Games events for the first time change over time. Moreover, understanding change in this way may offer nuanced ways of interpreting and analysing findings and changes within social networks.

There has been a wealth of literature that has adopted qualitative approaches to social network analysis (Bernardi, Keim, & Von der Lippe, 2007; Dominguez & Watkins, 2003; Edwards, 2010; Keim, Klärner, & Bernardi, 2009) yet, few studies have implemented a longitudinal design. Due to the lack of research in this area, it is difficult to determine the feasibility and potential ramifications of combining a longitudinal design with qualitative social network approach. In a review of the few studies which have attempted to address this gap, support has been granted for the usefulness of a longitudinal design in providing social network research with an opportunity to move beyond a snapshot in time. Furthermore, a

longitudinal design offers an opportunity to move away from retrospective limitations (Charania & Ickes, 2006), towards viewing networks as dynamic (Coleman, 1961). Coleman (1961) identified that social networks are in fact not fixed, but they transform through resources that flow through ties. Therefore, a longitudinal design makes it possible to examine the interplay between the micro and macro level, the individual change, the resources flowing through ties, as well as social structural changes over time (Lewis, 2007) which provides a rationale for its place within this study. Furthermore, Bidart and Lavenu (2005) stated that the structure of social networks is historically situated and elaborated over time.

Despite support for a longitudinal approach to social network research, Ryan and D'Angelo (2018) found that research did not capture the temporal elements convincingly. The authors suggest that research that has attempted to capture the temporal elements has done so through an overarching focus on network properties, often at the expense of the meaning and context. Ryan and D'Angelo (2018) noted that technological advancements and the development of software tools and computer modelling such as RSIENA and TERGMs have allowed for a better understanding of the dynamic relationships within social networks. Yet, there remains some concern that this new field of longitudinal social network analysis, with its technological underpinnings, would lack theoretical rigour and would return social networks to descriptive level understandings (Scott, 2011). Lubbers et al. (2010) suggested that descriptions of structural change over time provide an understanding of the dynamic changes but do not consider the micro level dyadic processes. The authors called for more attention on the content of ties rather than the existence of ties. Thus, a deeper level understanding of the content of ties would move beyond descriptive level understandings which provides further rationale for implementing a qualitative longitudinal social network approach within this thesis (Heath, Fuller, & Johnston, 2009). It is the qualitative component of longitudinal social network research that will account for the content and context of ties considering the micro level dyadic processes whilst still considering the macro level structural changes over time.

There are several limitations to the current qualitative approaches to social network research. Firstly, these approaches have been criticised for the lack of systematised integration of different analyses (Diaz-Bone, 2007). Research has not explicitly detailed the design of studies utilising a qualitative social network approach nor outlined a systematic approach to the analysis. The use of social networks with qualitative methods have been treated largely as mixed method approaches (Domínguez & Hollstein, 2014) despite being represented and described as qualitative research. This has contributed to the absence of well conducted

systematic qualitative examples due to lack of agreement in approaches taken. Further, future researchers attempting to combine types of analysis within a qualitative approach have been given little guidance to do so. Secondly, researchers have not been clear on the theoretical assumptions that have guided their qualitative approaches to social network analysis. Perhaps the lack of systematised combination of analysis has partially been due to the lack of theoretical consideration when combining qualitative research with social network analysis. For example, Granovetter (1985) suggested that interpretivists fail to relate social structures to discourses within which agents are embedded.

Another central criticism of longitudinal social network research raised by Ryan and D'Angelo (2018) is that it assumes change as one-dimensional and linear through interpolation between timepoints. That is, research comparing between two social networks at different time points to infer temporal changes. These criticisms are levelled at quantitative approaches. Considering the different types of change (Lewis, 2007), a qualitative longitudinal approach may offer a way to address these one-dimensional linear comparisons between social networks constructed at different time points. Further, Hollstein (2011) suggests that it is not only the fluctuating changes in networks over time that is important in longitudinal research but also the contextual changes. Understanding how the social context affects network structures may be a useful way in explaining change over time (Ryan & D'Angelo, 2018). Therefore, a qualitative longitudinal social network approach may be a useful way of addressing these contextual inferences to move beyond one-dimensional linear assumptions of changes over time.

Within this thesis, I adopt the view with Crossley and Edwards (2016) and Ryan and D'Angelo (2018) in that social worlds are complex which no singular method can capture on its own. Crossley and Edwards stated that researchers "can achieve more comprehensive and a more robust perspective by combining the vantage points that different methods afford" (Crossley & Edwards, 2016, p. 3). It is important to consider the extent to which a social network approach could offer qualitative longitudinal research an alternative way to understand social phenomena over time. That is, social networks could offer an alternative toolset to investigate social relationships and the embedded context with which relations are situated (Hollstein, 2007; 2011).

Overall, the criticisms outlined above will guide the choice in methods used within this thesis, to account for the temporal changes to structure and context of social relationships that

moves beyond the descriptive level understandings, to illuminate the embeddedness of narratives within social structure. In doing so, I will offer a systematised integration of different analyses that is theoretically informed.

3.3 Methods

Now that I have described the methodology and research approach to this PhD thesis, I will turn attention to the practical methods of data collection and analysis. Determining how these methods fit within the overarching methodology and research approach is essential to understanding its application to the research aims. Further, the methods will be situated within the aim of the thesis and will be justified in relation to their suitability and applicability in answering the research questions. First, the data collection process will be discussed along with outlining the sampling procedure and participant characteristics of the transplant recipient cohort involved in the study. Second, an outline of the data collection procedures which included the personal network creation task and semi-structured interviews will be discussed. I will then detail the steps taken within the data analysis.

3.3.1 Data collection

After gaining ethical approval from the University of Bath Research Ethics Approval Committee for Health (REACH), I contacted Transplant Sport UK to recruit participants. Transplant Sport UK is a national charity that promotes active recovery for transplant recipients through sport and social events. The charity's flagship event, the British Transplant Games, sees over 800 transplant recipients take part in over 20 different sporting events each year organised into Olympic-style competition. Each team that takes part in Transplant Games events represents a hospital or transplant unit within the UK and each team is managed by a team manager who organises the team and recruits new members each year. After permission was sought from Transplant Sport UK to recruit participants for this study, team managers were contacted to ask if they could extend a study invitation letter to transplant recipients who had recently joined their teams and were competing or had just competed in Transplant Games events for the first-time post-transplant. In this instance the team managers acted as the

gatekeepers to participant recruitment. Transplant recipients that matched the inclusion criteria were then invited to take part in the study. The study inclusion criteria were:

- have received a solid or non-solid organ transplant
- have participated in Transplant Games events for the first time
- aged 16 years or older

In addition to the recruitment through team managers from Transplant Sport UK, the World Transplant Games Federation were also contacted. The purpose here was to gain a larger and more diverse sample which included a wide range of transplant recipients' experiences of sport. The World Transplant Games Federation is an international association representing more than 60 countries in celebrating successful transplantation and the gift of life through staging international sporting events for transplant athletes which include the Summer and Winter World Transplant Games events held biannually. The aim of these events is to raise public awareness of the importance and benefits of organ donation through demonstrating the health and fitness of transplant athletes. Further, the World Transplant Games offer recipients the opportunity to strive towards full rehabilitation and offers a platform for recipients to pay thanks to donors, families, and health care professionals that made organ donation possible. After contacting the World Transplant Games Federation, they agreed to advertise the study through their website and social media platforms. Transplant recipients who showed an interest in the study adverts and who matched the inclusion criteria were invited to take part.

All the transplant recipients who initially agreed to take part in this study were provided with an information sheet detailing what participation in the study involved. Participants were then contacted over the phone and were provided with an explanation as to the level of commitment involved in this study. The participants were given the opportunity to ask any questions and could withdraw their interest in taking part if the involvement was thought to be too much of a commitment. Once participants agreed and prior to the first interview, a consent form was provided. Once participants had provided written consent, the first phase of data collection was arranged. At the end of the first interview, participants were asked whether they were happy to be contacted again in 6 months' time to arrange the second interview. The participants were reminded prior to each interview that their participation was voluntary and that they could withdraw from the study at any point. The data collection process lasted 12-months, after which participants were debriefed, reiterating the purpose of the study and how

the information collated would be used. The data collection process timeline is detailed in Figure 3.1.

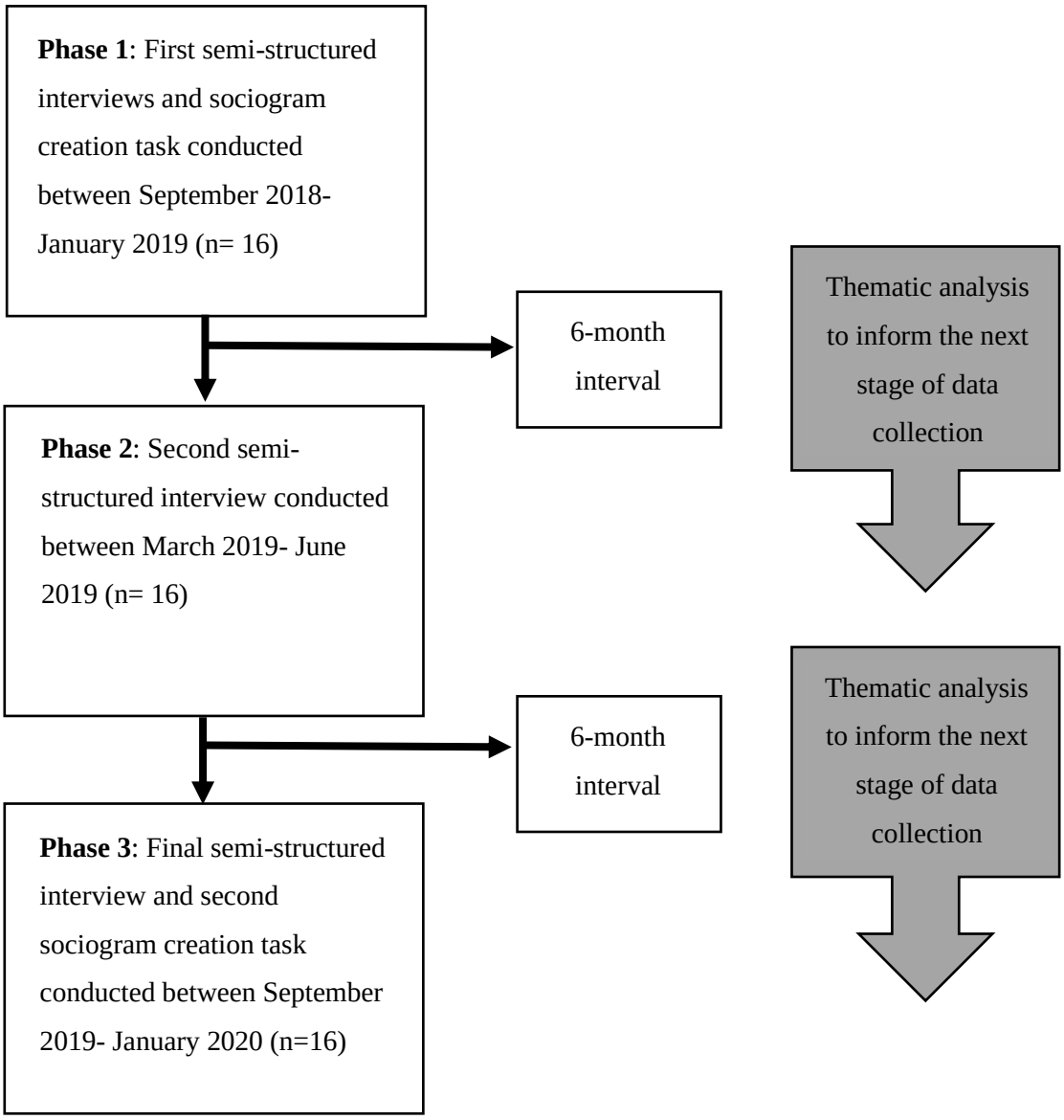


Figure 3.1 The data collection process timeline.

3.3.2 Participants

The participant sample included 16 transplant recipients, aged between 30 and 64 years old (mean age = 47) at the time of the first interview. Participants included eight females and eight males representing several countries including England, Ireland, Scotland, USA, Canada, Brazil, New Zealand, and Czech Republic. (see Table 3.1). The sample consisted of 14 solid-organ transplant recipients including heart (2), liver (5), kidney (7), liver and kidney (1) and two non-solid transplant recipients which included stem cell (1) and bone marrow (1) transplants, respectively. Purposeful sampling which was achieved through proactive recruitment through Transplant Sport UK and the World Transplant Games Federation ensured heterogeneity within the sample across gender, ethnicity, type of transplant, time since transplant and sporting competition.

Participants represented a variety of individual and team sports including athletics, cycling, racquet sports (i.e., tennis, badminton), field sports (i.e., football), indoor sports (i.e., bowling) and winter sports (i.e., curling). All participants competed in Transplant Games events within specific age categories and competed against a variety of competition levels, representing various transplants and illness trajectories. As such, the sample represented a variety of sporting backgrounds with some recipients having competed in sport for several years prior to transplantation, whilst others were new to sport, competing on a more recreational or social level. Some transplant recipients were restricted in what sport they could compete in because of their transplant type. For example, whilst there are no restrictions imposed by the organisers of Transplant Games events, heart, and lung recipients have different respiratory challenges to that of liver and kidney recipients.

As this thesis is concerned with the self-management and sport participation of transplant recipients, it was thought that discrepancies between transplant types, whether solid or non-solid, although largely varied, would involve similar levels of self-management. That is, participants would have to adhere to immunosuppressive therapies, maintain a healthy lifestyle and attend regular routine hospital examinations. A pre-requisite to being able to participate in the Transplant Games is to be a ‘recipient of a life-saving allograft or haemopoietic cell transplant from other individual(s) which require or have required the use of immunosuppressive drug therapies’ (WTGF, 2019). As such, all the participants included in this study had received, or were continuing to receive, immunosuppressive treatment since the start of the study.

The participants varied in the time since their transplants as well as their illness trajectories. Within the literature, the specific illness trajectories include the trajectory onset, acute illness, period of stability or instability, comeback, downward trajectory and dying (Corbin & Strauss, 1991). Out of all the participants, 15 were transplanted within the last 10 years with one participant having received a transplant 17 years prior to the start of the study. Further, the illness experiences across the participants are wide ranging with some experiencing prolonged and steady decreases in health over time, with others experiencing sudden and chronic illness or disease which led to receiving a transplant. As all the participants had engaged in Transplant Games events post-transplantation, it was thought that they had all entered the period of stability or instability according to Corbin and Strauss (1991) illness trajectory model. Therefore, the time since transplant was not considered critical to the aim of this study. Further, research has considered the uncertainties transplant recipients face post-transplant (Martin et al., 2010) which has included uncertainty around the threat of graft rejection (Forsberg et al., 2000; Nilsson, Persson, & Forsberg, 2008) and uncertainty around shortened life expectancy (Dudley, Chaplin, Clifford, & Mutimer, 2007). The uncertainties post-transplantation would contribute to the self-management experiences of the participants, as these are wide-ranging across the sample, this will provide further depth and breadth within this study.

A key consideration with this study is to what extent the sample constitutes a manageable number of participants whilst also considering the possibility of attrition within longitudinal research. Deciding on an appropriate number of participants was an important decision, especially given the nature and length of qualitative longitudinal research. According to research, rigorous research should be designed to include enough participants to reach saturation (Fusch & Ness, 2015). However, research with few participants generally produces rich data and allows for the participant and researcher to build relationships, develop rapport, and remove barriers to enable participants to feel at ease to discuss their experiences in depth. It was thought that the on-going contact between the researcher and the participants over a 12-month period would enable relationships to build and formal barriers to break down. Therefore, a sample of 16 was deemed sufficient given the longitudinal nature of this PhD thesis, the multiple data collection methods, and multiple interviews with each participant across timepoints. Research has determined that 50 interviews would constitute a large sample within qualitative research (Boddy, 2016; Sandelowski, 1995). As this study contains 48 interviews, it was thought that this would be sufficient in terms of depth and breadth across the 16 participants. Further, Boddy (2016) suggested that a sample size over 30 would be too large to

conduct meaningful and timely qualitative analysis. Therefore, the sample within this study was chosen based on what was pragmatically within the limits of what could be meaningfully analysed within the time frame of a PhD.

Table 3.1 Participant demographic information, type of transplant and sporting competition.

Participant Pseudonym	Gender	Age	Country of Residence	Transplanted organ	Number of Transplants	Year Transplanted	First Transplant Games Attended	Sport Competition	Attended Transplant Games since
Robert	Male	45	England	Liver	1	2014	British Games 2018	Javelin	Yes
Lauren	Female	30	England	Kidney	1	2016	British Games 2018	5KM Track Race	Yes
Michael	Male	58	England	Stem Cell	2	2014*	British Games 2018	Golf	Yes
Anika	Female	40	England	Kidney	2	2016*	British Games 2018	5KM Track Race	Yes
Daniel	Male	39	England	Liver	1	2016	British Games 2018	1500M Track Race	Yes
Courtney	Female	39	Czech Republic	Kidney	1	2017	British Games 2018	Badminton	Yes
Brian	Male	48	England	Kidney	1	2017	British Games 2018	Cycling 10KM TT	No
Ella	Female	36	Scotland	Heart	1	2014	Winter Games 2017	Curling	Yes
Jacquie	Female	64	England	Heart	1	2010	British Games 2018	Cycling 10KM TT	Yes
Silvie	Female	49	England	Kidney	1	2001	British Games 2018	5KM Track Race	No
Joseph	Male	48	USA	Liver	1	2017	USA Games 2018	Bowling	Yes
Claire	Female	41	Ireland	Kidney	1	2017	British Games 2018	5KM Track Race	No
Jeffry	Male	64	Canada	Kidney/Liver	2	2016*	Canada Games 2018	Cycling 10KM TT	Yes
Toby	Male	45	England	Kidney	1	2016	British Games 2018	Football	Yes
Paulo	Male	40	Brazil	Bone Marrow	1	2017	Brazil Games 2018	Tennis	Yes
Julia	Female	64	New Zealand	Liver	1	2015	Australian Games 2018	Cycling 10KM TT	Yes

*time since transplant refers to time passed since the second transplant in any instance where participants had more than one transplant.

3.3.3 Interviews and the sociogram creation tasks

This study consisted of a series of three semi-structured interviews and two sociogram creation tasks with each participant which were conducted either face-to-face or via Skype, over the 12-month study duration. Participants were guided in the creation of two sociograms using the participant aided interview based procedure outlined by Hogan, Carrasco, and Wellman (2007). A sociogram is a visual depiction of a personal social network which represents who a participant (known as the ego) knows and whether these individuals (known as actors) know each other (in the form of ties). Participants' sociograms were defined as the personal support networks important to their illness self-management and were created following a standard procedure outlined below. Participants created the first sociogram during the first interview (phase 1; 0-months) and the second sociogram was created in the final interview (phase 3; 12-months) of the study (see Figure 3.1).

The first phase of interviews (0-months) contained three parts. The first half briefly discussed the background and illness journey of the participant such as '*can you tell me about your illness and transplantation journey up to now?'* After each participant described their background and illness experiences, the sociogram creation task was then initiated. Here, participants were first presented with pink and orange sticky edged 'post it' page markers and were asked to write the names of people that they knew that they would define as either 'very close' or 'somewhat close'. The definition of 'very close' (people with whom you discuss important matters, with whom you regularly keep in touch, or who are there for you when you need help) and 'somewhat close' (people who are more than casual acquaintances but not 'very close') was provided to participants. The definitions of 'very close' and 'somewhat close' were adapted from Wellman (1982) as cited in Boase and Wellman (2006) and Hogan et al. (2007). Pink markers were used to denote 'very close alters' and orange markers denoted 'somewhat close alters'. Participants were then asked to indicate, with each name they had written on a tab, the alter's gender, age, involvement in transplantation and role in relation to them within the network. In any instance where participants named organisations, charities or other network members which did not resemble a person, gender was assigned as not specified (ns). See Table 3.2 for a full description of the network alter attributes and associated codes.

Several prompt questions were then provided, once participants had completed the entry of names, to encourage participants to remember additional alters that may be particularly important to their experiences of transplantation and self-management. Prompt questions asked

were, *'is there anyone additional who is important, influential, or supportive, in any way to your transplant self-management?'* and *'is there anyone additional who has hindered or hampered your self-management post-transplantation?'*. Finally, participants were asked to scan through the contact list on their mobile phone and social media accounts to ensure nobody that was important to their self-management had been forgotten. It was thought that the boundary specification of the personal networks needed to be explained here. The participants were not limited by how many network members they could add. If participants required more markers to denote network members, they were provided with more to do so.

The participants were then instructed to use an A2 sheet of paper marked with three concentric circles with 'you' in the middle and told that this was a visual representation of their 'personal social network' with which the lines represented perceived closeness to them (see Figure 3.2). Participants were then asked to place the pink and orange named markers onto the template according to how close they felt to that person. See table 3.2 for classifications of closeness within sociogram creations. Participants were instructed to place tabs within the circular lines and group tabs so that alters that knew each other were in roughly the same proximity. Finally, participants were asked to indicate any relationships that existed between all the alters that they had placed on their personal network map. This was achieved by drawing lines to connect alters that knew each other. Participants were instructed to draw a solid line around groups of 3 or more alters that knew each other (for example, close family members) to represent cliques that exist within the network. Dyadic relationships which represent a connection between two alters were indicated simply by drawing a solid line between the two tabs (see Figure 3.3 for an example of a completed sociogram). Following Hogan et al. (2007), I felt that it was important for participants to see their sociogram as the creation unfolded in front of them. Hogan et al. (2007, p. 117) stated, "the lack of visual depiction of networks at the data-gathering stage obscures data collection, because neither researchers nor respondents can see concrete representations of what they are discussing". In this way, it is the revealing and building of the participants sociogram that enriches the data collection process, builds rapport, and allows for an informative dialogue about each participant's personal social network.

After the participants had created their sociogram, it remained on the table for the participants to view throughout the remainder of the interview. Participants could revisit the sociogram at any point during the interview to add actors that they had forgotten. This is supported by previous research that has followed similar approaches (Ryan, 2011; Ryan, Sales,

Tilki, & Siara, 2008; Tubaro, Ryan, & D'angelo, 2016) as the relationships represented on the sociograms are central to the stories discussed within the interview. Further, the interviews often allowed time for the participants to recall other network members that were important. This is further supported by Hollstein (2011, p. 412) who stated; "mapping networks is a well-suited means of facilitating the discussion of relationships while it provides a strong stimulus for the production of narratives". In the same way that the interview jogged the memory of participants, the map also acted as a guide in constructing the narrative as participants often provided stories with each of the network members they included when reflecting on the positions of ties within their sociogram.

The second part of the first phase of interviews then explored the specific areas within the interview guide which enabled several topics to be discussed in more depth. The initial interview guide was created based on topics that had been identified from a review of the literature. To meet the aim of this study the initial interview guide focused on questioning around three broad areas: (1) personal social networks, (2) sports participation and the Transplant Games, and (3) self-management practices and experiences post-transplantation. The semi-structured interviews allowed for topics to emerge that had not initially been thought of that were considered important to the participant which could then be explored further over the duration of the study (Patton, 1990). The interview is therefore a co-construction between me as the researcher and the participant which is flexible (Cicourel, 1964). This enabled rapport to develop to ensure minimal drop-out over the 12-month study duration (Ritchie, Lewis, Nicholls, & Ormston, 2013).

The second phase of interviews (6-months) acted as a 'catch up' with participants who were invited to discuss any changes that had occurred over the last six months. For example, questions asked at this stage were, '*how have you been since we last spoke?'* and *'how has your health been over the past 6-months?'* Initial themes that were discovered from the analysis of the first phase of interviews formed the interview guide at this second phase. This offered the opportunity for participants to confirm the appropriateness of the initial findings which acted as a 'reality check', reducing a threat to validity. Topics that emerged from the analysis of the second phase of interviews then formed the basis for the final interview guide which topics included: the body and sport, duties as a transplant recipient, closeness experienced with transplant recipient contacts, and relationships with close ties. Finally, this stage allowed for me to check in with participants to keep them informed about the study and maintain their continued participation to avoid attrition.

The final phase of interviews (12-months) replicated the first interview in containing three parts which consisted of an update from previous interview followed by the personal network creation task for the second time. Participants were again instructed to create their sociogram following the same procedure outlined above in the first interview. After the participants had done so, they were invited to discuss any changes that have occurred over the last 12-months with regards to their sociogram. Questions were centred around the 'what', 'how' and 'why' of any changes experienced to their illness self-management support to elicit further dialogue and provide further context to explain any structural changes within their sociograms (D'angelo, Ryan, & Tubaro, 2016; D'Angelo & Ryan, 2019). For example, questions asked were, *'has your social network changed in the last 12-months?'* and if so, *'has the Transplant Games been significant or not to this change?'* and *'how has this impacted on your self-management capabilities?'* This was an important stage, central to the aims of this study. The second half of the interview then explored the specific areas within the interview guide which was based on previous interviews findings. For example, participants were asked, *'how do you think you have become aware of your body through participating in sport?' and 'how does sport impact on your identity?'* in relation to the initial finding of *situating the transliminal self and body through sport.*

The combination of the sociogram creation tasks with the interviews offers an approach to identifying the structure of relations whilst exploring the meaning and significance attributed to social relations. Further, the interviews provide the opportunity for 'thick description' and interpretation of relationships which view networks as dynamic and changing rather than a 'snapshot' in time (Bellotti, 2014). Research has seen value in moving towards understanding the meaning and value of exchanges between relational ties (Valente, 2010). Combining interviews with sociogram creations allow for the meaning and context of social relations to become realised through story telling.

Taking an iterative approach to data collection was chosen to identify concepts not initially conceived of at the start of the interviews. Further, this approach was used to identify culture-specific themes as they were constructed over time. This allowed for cycles of data collection and analysis to inform the next data collection cycle. Throughout the series of interviews participants were encouraged to speak freely about topics, perceived to be important and relevant, that emerged from discussion.

All the interviews were recorded using an audio recording device and were transcribed verbatim by myself as the primary researcher. In total, 48 interviews and 32 sociogram creations were completed with all 16 participants between September 2018 and January 2020 and each interview lasted between 47-90 minutes (average 65 minutes). The participants' second and third phase interviews were spaced 6-months apart to maintain a coherent interview process and keep within the 12-month study duration.

Table 3.2 Description of actor attributes within sociogram.

Attribute	**Coding description**
Actor colour	Represents Closeness: Pink/Red = Very close Orange = Somewhat close
Actor size	Represents positioning within network: Large = Centre circle (very close) Medium = Middle circle (somewhat close) Small = Outer circle (less close)
Actor shape	Represents involvement in Transplant Games: Circle = no involvement in Transplant Games Square = involvement in Transplant Games
Actor label	Represents relation to ego: 1a = close family 2b = spouse/ partner 3c = extended family 4d = friend 5e = work colleague 6f = medical practitioner 7g = neighbour 8h = someone online 9i = organisation or club 10j = transplant games 11k = other
Actor Gender	Represents node letter label: M = Male F = Female NS= not specified/other

Whilst I acknowledge that there may have been potential differences between the Skype and face-to-face interviews, I did not observe any differences in the quality of the sociogram creations or interview transcripts between face-to-face interviews compared with Skype interviews. I found that both were successful in gaining new insights into participants

experiences of their illness self-management networks. Research has supported the use of Skype interviews as an effective qualitative tool for reaching participants worldwide, increasing sample variety (Janghorban, Roudsari, & Taghipour, 2014; Lo Iacono, Symonds, & Brown, 2016). The ability to conduct Skype interviews further enhanced the heterogeneity of this study sample which included participants from eight different countries. With the Skype interviews that involved the sociogram creation task, participants were sent materials in the post prior to the interview so that they could create their networks during the interview. Participants were instructed to take a photo of their completed sociogram and send it over via email for analysis and interpretation purposes. A potential limitation of Skype interviews may be that they limit rapport (Janghorban et al., 2014). However, as this study offered prolonged engagement with participants over a 12-month duration, I did not see this as a limiting factor within this study nor did I feel it limited depth of conversation or engagement with the sociogram tasks.

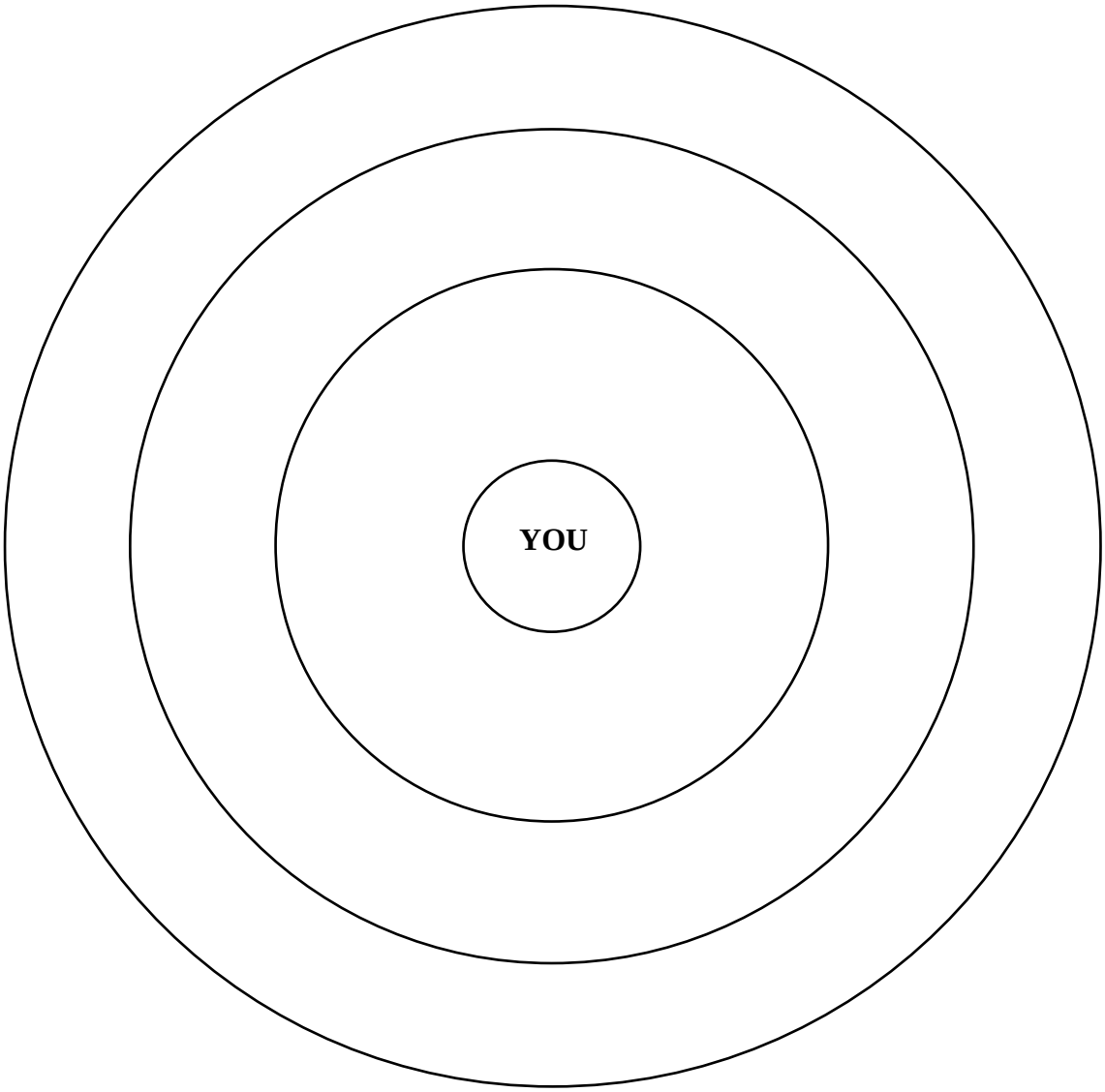


Figure 3.2 Example of a concentric circles map used during the interview to represent a participant's personal social network. The three concentric circles represent emotional closeness to YOU (the participant).

Figure 3.3 Example of a participants completed sociogram (anonymised). Lines drawn around and/or between tabs denote relationships between actors.

3.3.4 Data analysis

Data analysis was conducted in several stages to consider and account for the different types of data (see Figure 3.4). This staged approach to analysis was also carried out to ensure the analyses aligned with the aim of this study and answered the research questions. Furthermore, the different stages aimed to illuminate different elements including the temporal component of the longitudinal design. Overall, the multiple analyses carried out within this study fit within a critical realist approach through the notion of methodological pluralism, which asserts that particular data collection techniques are not aligned to a specific methodological or analytical approach therefore allowing for the choice of methodology, in this case, multiple analyses. Each analysis stage will be detailed and justified, in turn.

The first step of the analysis involved the thematic analysis of the interviews. Braun and Clarke (2006) thematic analysis was used here. Whilst the authors here present themselves as constructivists, thematic analysis is not wedded to a specific paradigm and as such would fit within a critical realist approach (Braun & Clarke, 2006). This flexible method allows for detailed and complex accounts of phenomena to be discovered. Both deductive and inductive approaches are possible with thematic analysis. The latter allows for themes to be constructed from the data enabling a 'bottom up' approach (Braun & Clarke, 2006). Here, the inductive approach fits within the aims of this thesis in better understanding transplant recipients' experiences of self-management, their personal social networks, and the impact of participation in Transplant Games events for the first time. Therefore, all the participants interview transcripts across all three interview phases were analysed inductively using thematic analysis (Braun & Clarke, 2006). However, caution is warranted in this approach as analysis is never purely inductive.

Thematic analysis first involved the familiarisation with the interview data which began when I transcribed the interviews (Bird, 2005; Riessman, 1993). Once transcribed, I commenced reading through each interview transcript in an active way of searching for meaning. During this stage I also familiarised myself with participants' sociograms to clarify the nature of relationships as they were spoken about. This allowed for a deeper immersion into the data than just repeated reading would have alone. From there, I generated initial codes which was achieved manually using Excel spreadsheets containing extracted Word document comments from the transcripts. Codes were created through the exploration of the data in keeping with the iterative bottom up approach. Coding was exhaustive as I aimed to code as

many potential patterns within the data as possible. After coding was complete, I began to search for themes. This involved collating codes into broader categories which were then reviewed and refined to ensure the coded extracts formed a coherent pattern relating to the theme. These themes were then reviewed in relation to the whole data set to ensure an accurate representation across the participants which led to naming and defining themes. After each interview phase, the transcripts were analysed to inform the next phase of data collection. This ongoing analysis enabled reflection of the data prior to the following data collection phases which enriched the narrative (Robinson, 2014) and final theme generation (Braun & Clarke, 2006).

The second step of the analysis involved the visual analysis of participants' sociograms. The sociogram data were entered into analysis software Netdraw, which is embedded within the widely used social network software UCINET (Borgatti, Everett, & Freeman, 2002). Netdraw is a computer assisted programme which generates a visual depiction of the sociograms which are coded to remove any identifying information. Netdraw allows for the same spatial representation of the alters and ties within the sociograms which were created during the interview through self-arrangement. Once the network diagrams had been created in Netdraw, visual network analysis took place.

Visual network analysis, as outlined by Decuypere (2020), is a holistic qualitative method used to visually interpret sociograms. Visual network analysis considers five topological dimensions important for the interpretation which include regions, centres, density, interfaces, and infrastructure. Regions refer to the concentration of actors or ties situated within a network. Centres are determined by the central actors situated within regions. Density considers the interconnectedness of actors and interfaces, referring to any overlap between different regions. Where overlap occurs, the actors which are situated between overlapping regions hold a boundary position and are considered important network members in connecting groups. The final dimension – infrastructure – is the demographic constitution of the members within a network. That is, the types of network members situated within specific regions. Once each of the five topological dimensions were considered across all the participants' social networks, they were written up as descriptions.

The descriptions of the topological dimensions of participants' networks across the 12-month study duration not only contribute to the presentation of results but also serve a purpose in further interpretation. Here, the descriptions were used to ask specific questions of the data

to determine change within and between participants' networks. For example, questions at this stage included, *'is there a difference between the topological dimensions of participants' networks?'* and *'do the descriptions of the topological dimensions of networks change over time?'* Asking these questions of the data helped identify where participants' networks either changed or stayed the same over time.

It is important to note at this stage, that the thematic analysis and the visual network analysis were not conducted successively and therefore these analyses could be achieved in a different order (see Figure 3.5). As I collected and analysed data iteratively, after the first stage of interviews and sociogram creation tasks, the interviews and the sociograms were analysed at the same time. It was important to move back and forth between these types of data as Decuypere states "the topological reading of the network is entirely co-dependent on the thick descriptions generated" (Decuypere, 2020, p. 12). Tubaro (2016, p. 7) stated that combining these approaches within the analysis "captures the dynamic interplay between how people talk about and visualise their social ties". This is further supported in the work of Ryan and D'Angelo (2018) who illuminated the success of the combination of analyses in understanding meaning within relational experiences. Providing context and meaning to individual personal networks is important to understand the context of change over time, as this may not be simply measured by an increase or decrease in network size or structural components such as density. Although network characteristics are important, they may not be able to fully explain the quality of ties in relation to transplant recipients' self-management on their own. Therefore, this provides the rationale for the combination of the analyses at this stage.

Following the visual network analysis, I compared the structural changes of participants' networks with the interview data to establish connections between how participants spoke about their networks in relation to the topological dimensions. This also offered an opportunity to provide context and meaning to the changes to the topological dimensions. The comparison and integration between the visual network analysis and interview data is an extremely valuable process which has been increasingly supported by previous research (D'angelo et al., 2016; Tubaro et al., 2016). Further, visualisations could be used within the analysis (as well as in the illustration of findings) to provide empirical grounding for the explanations and interpretations that emerge from the analysis process (Tubaro et al., 2016). Ryan and D'Angelo stated that, "visualisation can be used to bring methods into dialogue with each other, not necessarily to produce agreement but also to show tensions and discrepancies between data derived through different methods and thus provide new insights

for further analysis" (Ryan & D'Angelo, 2018, p. 151). If the thematic analysis themes related to the visualisations of networks, this would offer insight into the similarities between different methods and types of data. Moreover, the visualisations and interview data would offer a useful way to triangulate findings. In delineating the analysis of the network visualisations and interview data in this way, I offer insight into a novel approach to qualitative social network analysis. This will not only add to the scant literature on qualitative social network analysis procedures but will offer a detailed approach to act as a guide for future research, which can be built on and developed further.

The final step of the analysis involved a longitudinal component in the form of trajectory analysis (Grossoehme & Lipstein, 2016). Trajectory analysis uses sequential matrices to understand and illuminate change in individual experiences over time which can help in asking descriptive and interpretive questions of the data (Grossoehme & Lipstein, 2016; Saldaña, 2003). This is something that thematic analysis could not accomplish alone because it was carried out in a cross-sectional way, setting aside the longitudinal nature of the data. Furthermore, it was important to the aims of this thesis to consider the temporal elements to understand transplant recipients' experiences of participating in Transplant Games events for the first time and the impact on their self-management experiences over time. Therefore, I borrowed elements of trajectory analysis in the form of sequential matrices to organise the coded data and themes from the thematic analysis into tables for comparison between timepoints. The purpose here was to integrate elements of different analyses to help with one coherent analysis central to the aims of this study. I created matrices for each participant across all the themes that occurred across all timepoints (phases 1-3; 0-month, 6-month, 12-month). For each theme, I had created 16 matrices which positioned participants' data for each interview phase 'side-by-side' for comparison. The focus on this step of analysis is to determine whether change across themes did or did not occur over time. It was important to ascertain if there were specific 'gaps' within the matrices across the themes timepoints. Where there were gaps within the themes across time, it was thought that this may represent single variation over time (Grossoehme & Lipstein, 2016). However, caution is needed in the interpretation of these gaps as this could have resulted from the conversation being directed elsewhere in which case conclusions cannot be drawn. Despite this possibility, I ensured all participants were asked the same questions in line with the interview guide and the aims of this study.

Finally, the use of trajectory analysis in the form of the sequential matrices allowed me to identify interesting cases across the themes over time (Coltart & Henwood, 2012). Individual participant cases that represented interesting examples that illuminated change across the three timepoints were then presented as case studies alongside the trajectory analysis. The case studies therefore formed part of the trajectory analysis and were not considered an additional form of analysis. In this instance, one case was presented for each theme to provide further depth to the trajectory analysis. This approach allowed for a more focused longitudinal lens which produced thick description over time (Coltart & Henwood, 2012).

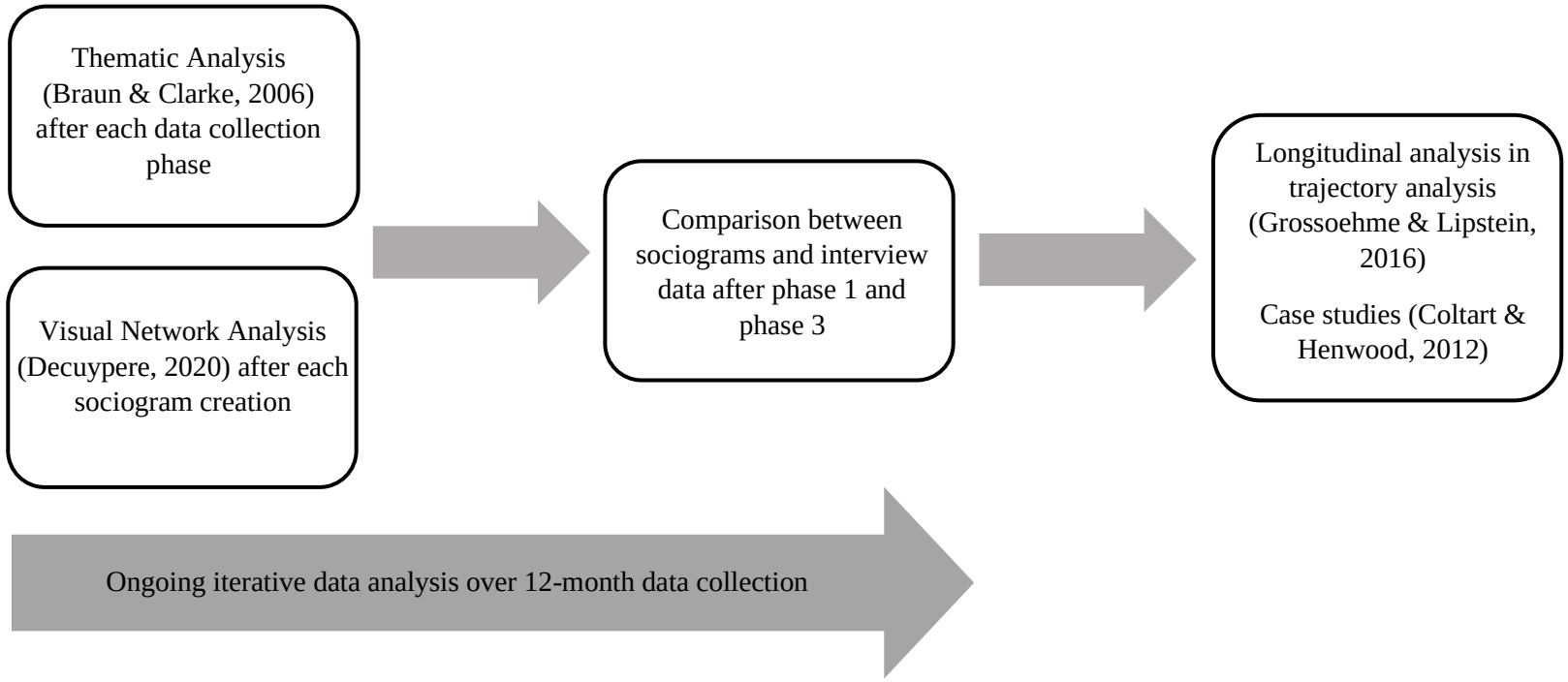


Figure 3.4 The data analysis process including the separate thematic analysis and visual network analysis completed after each phase of data collection. All three interviews produced a single thematic analysis whereas the sociograms completed at phase 1 and phase 3 were analysed separately and then compared together between and across participants during the comparison between sociograms and interview data. All thematic analysis and visual network analysis were completed before the longitudinal analysis and case studies were conducted.

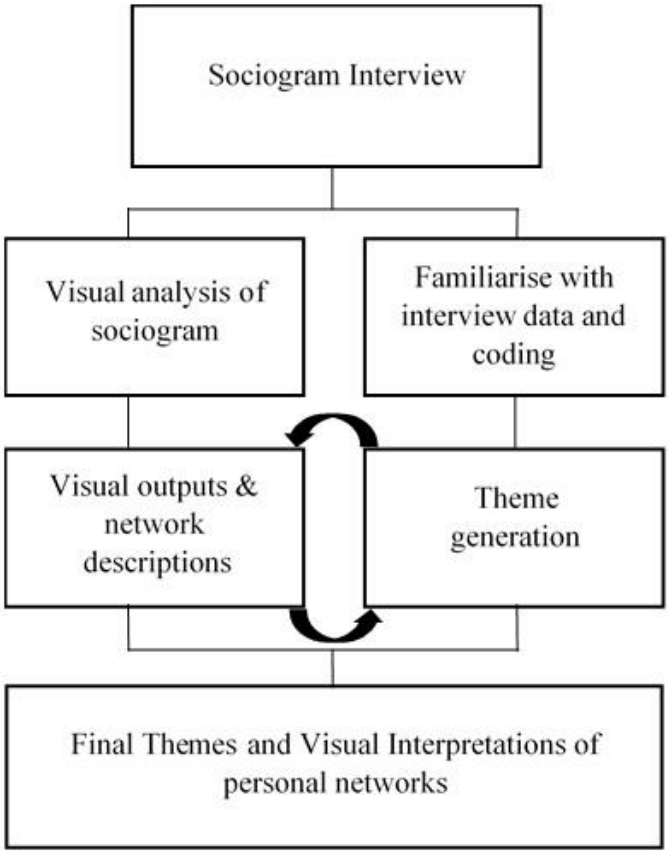


Figure 3.5 The thematic analysis and visual network analysis process in detail after each data collection phase (0-12 months). For the phase 2 interview, only the thematic analysis was conducted at this phase.

3.4 Validity of the study and my role as the researcher

There is much debate in qualitative social science research about ways of judging the knowledge claims made by researchers (Maxwell, 2017; Ronkainen & Wiltshire, 2019; Smith & McGannon, 2018). Many qualitative researchers have favoured the use of terms such as 'trustworthiness', 'rigour' or 'quality' when assessing the knowledge claims made by others' research (Ronkainen & Wiltshire, 2019). In doing so, researchers have often rejected the term 'validity' as it was considered inappropriate given its apparent alignment with the positivist paradigm. Despite this, this study will align with researchers suggesting validity should be a concept for judging scientific research (Hammersley, 1992; Maxwell, 1992, 2017). Maxwell (1992, 2017) outlined three types of validity which considers descriptive validity (accuracy of the qualitative research account), interpretive validity (meanings and perspectives held by participants), and theoretical validity (explanation through theory).

In line with Maxwell's (2017) typology of validity, I turn to the realist questions and procedures proposed by Ronkainen and Wiltshire (2019) to establish ways of working with the threats to descriptive, interpretive and theoretical validity. Through this guide I was able to assess how empirically adequate this study was by asking questions such as, *'how well has the descriptive validity of the research account been established?'* and *'how well have the limitations of data collection techniques been guarded against?'* Further, using these realist suggestions, I was able to ascertain how ontologically plausible the research account may be through questions such as, *'how well does the account engage theoretical explanation of the empirical evidence?'* and *'how thoroughly have the researchers engaged with competing alternative explanations of the evidence?'*. Finally, the realist questions looked to help establish how much practical utility this study has through questions such as, *'how well do the research claims guide practical actions in the real-world?'* These questions and possible procedures outlined by Ronkainen and Wiltshire (2019) will act as a guide for the measure of validity within this study (see Table 3.3).

This qualitative longitudinal study enabled prolonged engagement with multiple data sources from collection through to analysis which presented an opportunity for triangulation (Nowell, Norris, White, & Moules, 2017). The multiple methods used were complimentary of each other which are well supported and established methodological approaches. Furthermore, the use of the participant-aided sociograms during the interviews offered a way to seek validity through addressing the limitations of singular data collection methods as a way of seeking an

empirically adequate research account (Ronkainen & Wiltshire, 2019). Here, the sociograms acted as a tool to elicit deeper conversations about the relationships important to the participants' self-management experiences. Furthermore, combining types of data collection and analysis provided greater methodological pluralism in line with a critical realist approach (Wiltshire, 2018).

Saldaña (2003) suggested that longitudinal studies must consider the potential for change in the type of data collected and the data collection methods used for longitudinal research. As I conducted all interviews and transcriptions, enhancing the overall quality, integrity, and credibility of the data collection process, it was thought that changes in the data would provide depth and thicker description. Further, this offered an opportunity for prolonged engagement with the participants which increased my confidence that adequate data had been collected to support later interpretations (Ronkainen & Wiltshire, 2019). Moreover, as the interview process was iterative containing three phases over the 12-month duration, data analysis was also an on-going process which allowed for the data collection methods to become more specified and refined after each phase. As Schwalbe and Wolkomir (2002, p. 16) stated:

> To delay analysis until "all the data are in" is to miss the chance to make midcourse adjustments and go after precisely the data needed to strengthen an emerging analysis. In this way, not only is the interview increasingly refined, but the analysis itself gains strength and focus as the study proceeds.

The iterative data collection and analysis was a pivotal component of this PhD thesis in which initial themes would be used to guide further questioning. As the interpretations of these initial themes are pivotal to the following interviews, a discussion with my supervisors throughout data production was maintained. I discussed with my supervisors the interviews, my approach to questioning, the transcripts, and the ongoing theme development. These discussions were particularly useful to ensure that my own interpretations were an accurate representation of the accounts heard. Moreover, the iterative thematic analysis used to inform the following data collection phases, enabled further depth to be explored which enriched the overall quality of the interview data. Further, this prolonged my engagement with participants as I became immersed in their experiences.

It is important to note that as the researcher I became a part of the data collection process which required a reflexive approach to account for my own personal bias (Holloway & Biley, 2011). To account for this, I kept a reflexive log throughout the data collection and analysis phases to acknowledge and make visible any assumptions I held throughout the duration of the

study (Ortlipp, 2008). The reflexive log was used to help gather my thoughts, values and assumptions throughout the study duration and enabled me to reflect on key moments which guided the analysis and findings discussed later. The reflexive log enabled me to keep track of participants' journeys over time which was crucial to maintaining rapport with each participant and acted as a way of acknowledging the temporal elements of change which could easily become blurred.

Another important consideration as my role as the researcher was my changing perspectives over time which could threaten validity but also enhance it through gaining empathy to move closer to the truth. When conducting interviews, I was aware of how participants may have perceived me. I was aware that at the beginning of the study I felt like an 'outsider' to the transplant community as I was not a transplant recipient or donor, nor did I know anyone who was. My exposure to the transplant community certainly changed my perspectives over time as well as my views on organ donation and transplantation. Shortly after the commencement of this study, I registered as an organ donor, something I had given little thought to in the past. On several occasions, I had been asked by participants during the interviews whether I was registered as a donor. The significance of registering as a donor has dominated the organ transplant narratives given the current supply-demand gap and lack of suitable organ donors. Further, the participants felt an obligation to raise awareness and become an advocate for organ donation. This is something that emerged throughout the study but also something I was conscious of before and during data collection. The decision to become an organ donor was an easy one for me given the proximity of the research project. However, it is important to be aware and reflect on how my changing perspectives on organ donation and transplantation influenced this study. Here, reflecting on my own bias and changing perspectives was a way of reducing the threat to validity (Ronkainen & Wiltshire, 2019). Furthermore, as the primary researcher, it was not possible to exclude myself from the data collection, interpretation, and reporting of this study. It is therefore important to consider the impact of myself situated within this PhD thesis and how I, as the researcher, have influenced the process detailed throughout. Ongoing critical reflection of my role within the data collection and analysis further acted as a measure of rigour.

Finally, this PhD thesis required prolonged commitment from the participants over the course of a 12-month duration. With this, I was aware that transplant recipients may have felt obligated to take part in this research study as a way of giving something back, part of their 'duties' in being a 'good recipient'. This is something I became more aware of as the study

progressed and initial themes were discovered. Whilst on-going consent was sought prior to each interview in accordance with ethics, participants were reminded that this study had no impact on their aftercare with formal healthcare providers or impacted on their place within the Transplant Games teams. Further, I do not believe that recruiting through Transplant Sport UK and the World Transplant Games Federation influenced what participants shared with me. My relationship as an independent researcher, not being associated with any of these organisations, was reiterated to all participants. The participants were further reassured that the interviews would not have an impact on their ongoing relationships with either Transplant Sport UK or the World Transplant Games Federation to ensure accuracy of accounts shared from participants.

Table 3.3 Adapted realist suggestions containing questions and procedures applied within this study to work with threats to descriptive, interpretive, and theoretical validity (Ronkainen & Wiltshire, 2019).

Questions	Procedures	Self-evaluation within present study
How empirically adequate is the research account?		
1. How well has the descriptive validity of the research account been established?	Transcription checking, timely note taking, multiple researchers establishing descriptive accuracy.	I sent all the transcripts and initial themes to participants to act as reality check although this prompted little engagement from participants other than confirming the accuracy of the data.
2. How well have the limitations of data collection techniques been guarded against?	Multiple methods, mixed methods, triangulation, prolonged engagement with participants.	Multiple methods offered triangulation and 12-month study duration enabled prolonged engagement with participants which offered rich insights into individual accounts. I felt as though I had become an insider within the transplant community. Iterative data analysis informed successive data collection.
How ontologically plausible is the research account?		
1. How well does the account engage with theoretical explanation of the empirical evidence?	Drawing on existing theory, positioning hypothetical statements.	Themes discussed in results and discussion chapters in relation to theory and previous research.
2. How thoroughly have the researchers engaged with competing alternative explanations of the evidence?	Using critical friends, member reflections, formal peer review, disputative conversations, multi-researcher independent coding.	Themes and transcripts discussed with supervisors throughout 12-month study which was constantly revisited during each stage of iterative data collection and analysis.
How much practical utility does the research account have?		
1. How well do the research claims guide practical actions in the real-world?	Proposing practical suggestions, outcome prediction.	Implications and contributions of research highlighted within the discussion to inform future research and practitioners.

3.5 Ethical considerations

Due to the longitudinal nature of this PhD thesis and the likelihood of participants' circumstances changing over time, written consent could not be assumed throughout the duration of the study. France, Bendelow, and Williams (2000) suggested that consent is an ongoing process rather than a one-off process. Therefore, ongoing consent should be sought throughout the duration of a study. Therefore, written consent was confirmed before the first interview and verbal consent was sought prior to each following interview. It was thought verbal consent is consistent with the ethical principles of participant autonomy.

Another key consideration of the ethical issues is that of the fluctuating health of the transplant recipients involved in this longitudinal study. Participants had to deal with a suppressed immune function, balance demanding medication regimens, and maintain a healthy status as to avoid additional illness or infection. Two participants went into rejection at different stages of the study between interviews. Despite this, the participants had returned to stable health before the commencement of any further interviews. The temporal aspect of this study was being managed differently between participants and myself as the researcher. It was important to understand the complex health status of participants and ensure the study did not impose any burden. However, prior to participation in Transplant Games events participants are required to undergo medical examination and receive sign off from their transplant consultant to confirm that they are healthy to compete in sporting competition. Therefore, participants taking part in the study had been fit to do so.

Of central importance to ethics is the welfare and confidentiality of the participants who participated throughout the duration of this PhD thesis. Confidentiality is a key principle of ethical research which involves the non-disclosure of any confidential material. This is critical when considering social network data (Borgatti & Molina, 2005). To ensure confidentiality was met procedures were put into place, with a unique code and pseudonym allocated to each participant prior to data collection. This code and pseudonym were used as the sole identifier for all information collated in relation to each participant. Further, the sociograms created during the personal social network task during the first and last interview were anonymised using relationship codes (see Table 3.2). This was to ensure anonymity and confidentiality of the sociograms when they were presented in raw data form. Within the presentation of the sociograms in the analysis, data went through digitalisation using Netdraw which reduced all identifying information into visual relational codes. Throughout data collection process the

network diagrams were stored separately away from the transcripts and audio recordings to ensure identification could not be inferred.

Prior to the interview, participants were made aware that they could pause or cease the interview at any point, stopping the recording or withdrawing completely at any stage from the 12-month study. Due to the nature of semi-structured interviews, unexpected information may emerge over time (Lee, 1993). To establish trust between the researcher and participant I ensured that the participants were comfortable and were in control of what was being discussed. As the interviews were of a semi-structured nature, it gave participants a degree of control over what was discussed. Beyond this, participants were assured that the interviews were an opportunity for them to share their experiences of self-managing transplantation and it was felt there was a minimal risk to participants and that the interviews would resemble day-to-day conversation. Participants were made aware that this study will look to understand how these experiences change over time with an emphasis on their relational changes through sport participation.

Finally, data was processed in accordance with participants' rights, kept secure and encrypted. The transcripts, sociograms and social network data were stored within an encrypted folder within the lead supervisors managed data storage to which only supervisors and I have access to. The data collected in this study may be used in future projects although participants were informed and had to agree permission for this which was reflected in participant consent.

3.6 Summary

In this chapter I have described the research approach underpinning this thesis and have detailed the methods used in data collection as well as the techniques within the analysis. This chapter also highlighted how this study met the standards of validity and how my role as the researcher developed throughout the study which will impact the interpretation and discussion to come. Finally, I outlined the ethical considerations within the qualitative multiple methods longitudinal approach to this study. In the next four chapters I will present the results of this study. In Chapter 4, I will present the characteristics of transplant recipients' illness self-management networks. Chapter 5 will then present the longitudinal aspects of participants' illness self-management networks. In Chapter 6, I will explore the themes generated from the

thematic analysis of the 48 interviews across the three phases of data collection of this 12-month study. Finally, Chapter 7, will present the longitudinal component of the thematic analysis and consist of the results from the trajectory analysis in the form of sequential matrices. The trajectory analysis and sequential matrices will then inform the participant case studies which will be presented within this results chapter to act as examples to illustrate change across the themes over time.

CHAPTER 4: CHARACTERISTICS OF ILLNESS SELF-MANAGEMENT NETWORKS

4.1 Introduction

This chapter will present the social network data from the 32 sociograms created during the interviews. Participants were tasked with creating two sociograms across the 12-month study duration with the first created at phase 1 (0-months) and the second sociogram created at phase 3 (12-months). The sociograms were defined in this study as the personal support networks important to participants' illness self-management and are therefore referred to as illness self-management networks. This chapter will address the following research question; *'What characterises the illness self-management networks of transplant recipients who have participated in Transplant Games events for the first time?'* I will use the interview data throughout this chapter to provide context and meaning to the interactions with network members and the relationships between them. I will begin by explaining the basic components of participants' social networks detailing the network size in terms of the amount of network members and connections present within the networks across all 16 participants. I will then outline the various types of network members and support within the networks before outlining the overall types of networks participants have. The topological dimensions from the visual network analysis which include regions, centres, density, interfaces, and infrastructure will be used to identify the types of networks.

4.2 Size of participants' illness self-management networks

Discovering the size of participants' social networks may be useful in better understanding how participation in the Transplant Games may influence this. Participants could include anyone they felt was important within their illness self-management networks. In some cases, this included organisations and donors which played an important role within participants illness self-management. Further, there was no limit on the number of actors participants could include. Table 4.1 presents a summary of the number of actors and ties present within participants networks at phase 1 and phase 3.

Across all networks, eight participants (Lauren, Anika, Daniel, Courtney, Brian, Jacquie, Silvie, Jeffry) had a smaller network at phase 3 then their phase 1 network. Out of these eight participants, Silvie had more ties within her phase 3 network despite a reduction in actors. This would suggest that although Silvie's network was smaller in size it had become

more connected. Participants also discussed how their networks had reduced in size due to not requiring support in managing their transplant. As Jeffry stated, "I think my network has got smaller cause some people are used to me doing this thing, so they don't think I need any encouragement". This was further articulated in the way Lauren narrated the changes in her social network:

> I think it has changed a bit. Obviously, it looks like it has shrunk but it kind of has and hasn't. Some people have moved in close and some people have moved away because of time. Even though my network is smaller than it was a year ago I think that I am better at managing things myself and less reliant on people before.

The significance of this moment of being able to self-manage their own health, moving away from illness, impacted the way participants positioned and perceived their support within their network which impacted on the overall size of their network. However, participants often acknowledged that their health status may change in the future, with which the perceived importance of certain types of support would also change whereby their network may increase consequently. For Claire, this sense was captured in the way she spoke about the changing nature of her network and future health:

> The thing about dialysis and transplantation as you know, you are not cured. Transplantation is a treatment, and I am very realistic about that. I know these people are going to weave in and out of my life for as long as I live. I do not know how long this kidney is going to last me, but I am very realistic that way. Well things are going well you just roll with it. If you are to come to me in 10 years' time, this could be totally different, my network could be totally different.

Participants reflected on the dynamic nature of the characteristics of their illness self-management network and how the size of their network could change dependent on their health status. However, one participant, Robert, did not experience any change in the size of his network over the 12-month study duration. For Robert, the number of actors and ties included within his network was consistent across phase 1 and phase 3.

The remaining seven participants (Michael, Ella, Joseph, Claire, Toby, Paulo, Julia) all experienced increases in the number of actors within their networks between phases. Michael summarised the increase in network size well in how his illness self-management network was going to get bigger. As Michael moved towards being healthy, he predicted that his network would consequently increase in size. Michael situated his network as wide reaching with network members situated across the world who have been important to his illness journey. Michael discussed the strength of his network:

> I think my network has just got stronger with the fact that I have got back to work. I think it has really got stronger now. The element of doubt has gone, plus the fact now that I am 5 years post-transplant. So, the longer you go with a transplant the better. My network is going to get bigger as well. The indoor football group are a whole new set of lads.

Whilst Claire's network at phase 3 was larger than her network at phase 1, she spoke about how she had come to manage her own health which impacted the construction and size of her network. Claire stated:

> Because I am doing so well medically, I am not being seen as often [by medical support] as I am fixed now. Well not fixed but you know, you kind of have to leave a few of the people that were close to you behind because you have progressed on to another, better self. Well not better but I do not know, she [dialysis nurse] was in my support network, but she is not anymore.

For Claire, she had moved towards being healthy which reflected the frequency of support that she no longer required and perceived as important had reduced rather than the actual size of her network. The medical support in her dialysis nurse and transplant consultant were perceived as less important and as such contact had reduced. Further, Claire assumed responsibility for managing her own health as she said, "I am very aware that I have to manage my condition at home, but he [consultant] knows I am very compliant. I ring and make sure my bloods are okay. I do not wait for there to be a problem. I believe in self-management and he knows that". In this way, Claire had made space in her network for other members given her focus away from the amount of medical support she needed. Similarly, Ella reflected on how she no longer required certain types of support which enabled her network to increase in size. Ella discussed how she had become less reliant on the support of others who were experiencing similar health concerns as she was capable of self-manging and was seeking normality. She said:

> I think immediately post-transplant it was really helpful. You know if people were worried about their hair falling out or their medication or 'are you worried about this?' We have had discussions about all this. But I think now, 5 years post-transplant, I think I am less reliant on those people because I would like to say I can self-manage it. I have lived with it long enough, it is part of the routine, and it becomes normal.

Here, Ella had moved towards resuming a sense of normality which for her meant positioning her network away the medical and emotional support from other transplant recipients.

For Julia, her network increased the most dramatically from 24 actors to 60 at phase 3. Two participants, Ella and Paulo had less ties despite having increased overall network size (see table 4.1). This would suggest that despite increasing network size the actors had not

become integrated within the rest of the network to establish further ties. This may explain how Transplant Games actors represented as weaker ties are situated within a network influencing the size and connectedness of participants networks.

Table 4.1 Participants' personal social network size across phase 1 (0-months) and phase 3 (12-months).

Participant Pseudonym	**Number of Actors**		**Number of Ties**	
	Phase 1	**Phase 3**	**Phase 1**	**Phase 3**
Robert	29	29	140	140
Lauren	17	12	102	34
Michael	27	42	248	766
Anika	21	16	118	110
Daniel	15	9	28	26
Courtney	11	9	30	22
Brian	19	14	76	38
Ella	41	44	264	262
Jacquie	53	34	646	104
Silvie	14	10	28	38
Joseph	16	20	72	188
Claire	27	29	240	428
Jeffry	18	13	66	36
Toby	17	29	154	160
Paulo	17	20	102	96
Julia	24	60	64	540
Total	366	390	2378	2988

Overall, participants' networks varied in the size with half of the participants networks increased and the other half decreased which could be seen from looking at the network data alone. Despite the varied changes in the size of networks, most participants positively perceived this change. Those who experienced a decrease in overall network size explained this through not requiring the same level of support they had received at phase 1, becoming self-sufficient with their illness self-management work. For some participants who had a larger network, they explained this through increased activity levels as they resumed normal functioning, returned to work, and resumed or started sports participation. In some cases, participants attributed the

change in the size of their network to participating in the Transplant Games. For example, Paulo stated: "what changed is that I know more people now, Brazilians who play sport and people I met at the World Transplant Games in Newcastle and I have new friends now". Jacquie also articulated this when discussing the impact attending Transplant Games events for the first time had on the size of her network. She stated:

> I have put them [Transplant Games members] on the inside of the network [very close]. The British team were very, very supportive of one another. My relationship with the Papworth people, with the team and also making relationships within the British team because a lot of them, you don't only see the British team at the World Games but also at the British Transplant Games in their hospital teams, so you renew friendships and there is a couple of the lads who are cyclists who we Facebook on a regular basis. The more friends you are making the closer you are getting.

Finally, whilst the size of networks may illuminate certain characteristics of networks, further enquiry, and analysis into other characteristics of participants' illness self-management networks is warranted including an understanding of the types of network members and support work included within their networks as well as understanding the overall types of networks.

4.3 Types of network members and support within participants' illness self-management networks

Participants displayed varied networks representing a wide range of actor relationship types that were considered either very close, somewhat close, or less close across both phase 1 and 3 networks. The main network member types were close family, spouse or partner, friends, medical practitioners, and Transplant Games members (see table 4.2). Across all 32 social networks, participants had placed close family within the very close category and participants who had a spouse or partner also positioned these actors within the very close category. Within the interviews, most participants discussed how their close family, and spouse or partners were very close in relation to other members. Ella stated, "I suppose my inner circle is mostly family, and one very close friend".

Friendship actors were more evenly distributed within participants' networks between very close, somewhat close, and less close. The friendship actors were also the most frequently included network member within participants' networks with 131 friendship actors out of a total of 366 actors included within phase 1 networks, and 184 friendship actors out of a total

of 390 actors included within participants phase 3 network. Medical practitioners were mostly situated within the somewhat close and less close category with only a few medical practitioner actors positioned as very close within a few participants' networks. Most participants often discussed the consistency of medical support staff through regular check-ups and hospital visits. For some participants who had experienced illness or experienced sudden health declines, they discussed the significance of medical support which directly influenced the placement of these actors within their networks.

Transplant Games actors were positioned within all three categories of closeness, although most of these actors were situated within the somewhat close or less close categories. Furthermore, having competed in Transplant Games events for the first time, Transplant Games actors were largely discussed within the interviews as less close. However, for some participants, Transplant Games actors held more central roles within their networks. Conversely, two participants spoke about distancing themselves from the transplant community and transplant contacts to resume a sense of normality and therefore had not positioned any Transplant Games actors centrally within the very close category.

Table 4.2 Relationship type of actors situated within each category of importance within all participants' social networks across phase 1 (0-months) and phase 3 (12-months).

Relationship Type	**Large sized actor (Very close)**		**Medium sized actor (Somewhat close)**		**Small sized actor (Less close)**		**Total number of actors**	
	Phase 1	*Phase 3*	*Phase 1*	*Phase 3*	*Phase 1*	*Phase 3*	*Phase 1*	*Phase 3*
Close family	64	47	7	8	0	0	71	55
Spouse/ Partner	13	13	0	0	0	0	13	13
Extended family	12	17	8	13	4	0	24	30
Friend	33	59	67	69	31	56	131	184
Work colleague	2	2	3	4	1	4	6	10
Medical practitioner	6	3	21	14	29	20	56	37
Neighbour	0	2	1	1	0	0	1	3
Someone online	0	0	0	0	1	1	1	1
Organisation or club	2	3	10	7	16	8	28	18
Transplant Games	3	2	19	5	13	32	35	39
Total number of actors	135	148	136	121	95	121	366	390

The types of support participants sought from their illness self-management network included illness work, emotional work, everyday work, and sport work. Courtney described this well in the various types of support she had received from her closest network members which included her romantic partner and badminton partner from competing in Transplant Games events. Courtney said:

> It would cover all aspects of emotional, every day, sport, and transplant work. Because again with badminton partner we do discuss sport, we do discuss transplant, and we do discuss everyday life. We discuss about our emotional impact on anything that is going on. With my romantic partner, obviously as a partner, we should be talking about these things regardless. With my romantic partner, it is probably less about sport because she is not the sportiest person in the world.

Similarly, for Jeffry, he spoke about different types of support within his network. He acknowledged the illness work, everyday work, and sport work he received from other transplant recipients and how emotional work was unconditional from his family. Jeffry stated:

> Some of the support [from transplant recipients] is kind of technical basis like sports advice and training. Some of it is just moral support from other transplant people who have been in the same situation as me. And then there is the family who have to love you.

Ella reported similar types of support received from the closest members in her network. She explained, “I suppose family are probably a bit emotional and practical support. But then again, I am not sure the practical support is necessarily to do with the heart transplant it is to do with having twins that are five”. For Ella, she attributed the types of support based on her life situation in that she had two twins to look after, rather than managing her transplant. Participants often expressed how this support was consistent within their inner networks, members considered very important to participants illness self-management post-transplant. Silvie supports this further as she describes the support of her husband. She narrates, “So husband is the same influence as before, I guess luckily, he likes exercise and he looks after himself- he is a big impact on me and that helps”. For Silvie, her close support network signified healthy practices in accordance with her own illness self-management.

The perceived importance of each type of support varied based on the health status. For participants who experienced a decline in their health, they positioned their network towards illness work as they perceived their emotional work, everyday work, and sport work as less important. An example of this was observed in comments made by Joseph who acknowledged how a worsening kidney function had influenced the closeness and proximity of his network members. He explained:

> It is so funny, one person that was a pink [very close] a year ago is now going to be an orange [somewhat close]. It happens I got to be very close with people in my support group. I have had five people come forward to offer their kidney for donation. But I will not take a kidney from a close friend or family member in case they need it down the road. But there is a lady in my support group whose husband had a liver and kidney transplant and she had made a decision long before she met me that she would like to donate her kidney to someone when she met the right person that needed it. And now she has told me that whenever I needed it, it is there.

Here, Joseph understanding of his worsening health and the potential need for a kidney transplant in the future influenced the way he perceived and structured his illness self-management network. Those perceived as more important and closer to him as he witnessed worsening health, provided illness work which he required.

Conversely, some participants looked to move away from illness work and position their network away from others who represented illness. For Julia, she felt the need to position her network away from liver transplant support groups that she had been a member of since her transplant. She said:

> I do actually think my network has changed. I used to be in a support group, but I cancelled out of it because I thought it was hideous. In New Zealand, 65 percent of liver transplants are IV drug use or alcohol related. And I probably decided that I did not want to be part of such a group of people, I found them quite sorry.

Overall, the types of network members and support within participants' networks influenced the meaning attached to illness self-management. These relationship types influenced how support was perceived, sought, and received which was also dependent on the proximity and closeness of actors. I will now explore the types of networks to further understand the characteristics of participants' illness self-management networks having participated in Transplant Games events for the first time.

4.4 Network types

Despite the diverse types of actors populating different regions within participants networks, four main types of networks were identified. By identifying the size and topological dimensions including the regions, centres, density, interfaces, and infrastructure of participants' networks and their perceived importance through the qualitative explanations, networks could be categorised as: family-focused networks, friend-focused networks, family-friend-focused

networks, and diverse-sport-focused networks. Although different network types are apparent across participants within this study, the boundary between these network types remains blurred. Not all participants fit neatly into a certain network type, however the criteria for inclusion to each network type was standardised across all participants to ensure consistency in the identification and classification of network types. Table 4.3 highlights the criteria and characteristics of each of the four types of networks. The network types were constructed empirically and are only illustrative of the social networks of the participants included in this study and are therefore not exhaustive or generalisable beyond the reach of this thesis. Each network type will be discussed in turn supported with participants interview data and network visualisations to further illustrate the types of network.

Table 4.3 The criteria and characteristics for the four types of networks.

	Criteria for inclusion		
Type of network	**Inclusion of actors**	**Topological dimensions of network**	**Interview data explanations of network**
Family-focused	Family actors outnumbered other actors including friends and Transplant Games actors	Family actors considered within main region and centrally positioned within network	Interview data extracts from phase 1- 3 are illustrative of importance of family actors and the meaning attributed to this type of support
Friend-focused	Friend actors outnumbered other actors including family and Transplant Games actors	Friend actors included within majority of regions and centrally positioned within network	Interview data extracts from phase 1- 3 are illustrative of importance of friend actors and the meaning attributed to this type of support
Family-friend focused	Family and friend actors were equal within network	Family and friend actors equally distributed within regions and positioned centrally	Interview data extracts from phase 1- 3 are illustrative of importance of family and friend actors and the meaning attributed to this type of support
Diverse-sport focused	Combination of Transplant Games, family, friend, work colleague, medical practitioner, and organisation actors	Transplant Games, family, friend, work colleague, medical practitioner and organisation actors distributed evenly within regions and positioned centrally	Interview data extracts from phase 1- 3 are illustrative of importance of various actors and the meaning attributed to this type of support

4.4.1 Family-focused networks

Family-focused networks consisted of mostly family actors which outnumbered other relationship types and were perceived as very close. These actors were also positioned centrally within participants networks. Four participants (Anika, Claire, Jeffry, Michael) had family-focused networks at phase 1. Within Anika's and Claire's networks, they had one core family region which were all perceived as very close and were positioned centrally. Figure 4.1 displays Jeffry's network composed of a core region of his close family and spouse which he perceived as very. The family focus of Jeffry's network was further evident in how he spoke about his close support within the interview. He said:

> So, family was definitely the closest, just kind of expressing their concern within the family and expressing their love. You say things you wouldn't necessarily otherwise when someone is going into surgery, some of those things that usually get left unsaid, get said.

For Jeffry, it was through being ill and going through transplantation that brought his family close. Interestingly, Jeffry also discussed how his wife had offered to be his donor which brought them closer together. He said, "my wife volunteered to be a kidney donor for me, and she was a match which was kind of neat that after 30 years of marriage we then had clinical evidence that we were compatible… I think it did a lot for our relationship". Here Jeffry provides further support for the central position his wife occupied within his network.

Across phase 3, five participants (Anika, Claire, Michael, Brian, Paulo) had family-focused networks. For Anika, Claire, and Michael, this was consistent across both networks at phase 1 and phase 3. Anika's network again represented one core family region all perceived as very close. Similarly, Claire had one large core region consisting of mostly family actors perceived as very close. Although, within Claire's network, her family region was integrated with another region consisting of friends and medical practitioners. Michael offered an explanation as to why his network was family-focused which he explained was because of the difficulty in meeting with other Transplant Games actors due to the geographical location of the team he represented at the Games. He stated:

> I mean on the one hand, I'm glad I did what I did for Antony Nolan but on the other hand, I perhaps wished I had gone with Birmingham hospitals because I could of then picked up another social circle. I cannot do that with Antony Nolan, until the Games.

Michael acknowledged the challenges of meeting with other Transplant Games actors but also offered some future focused reflections on how he perceived the Games to impact on his network. Michael stated:

> With this being my first Games, over time the network should increase. Because there is a separate six a side tournament and there may well be a separate golf tournament. So, there is a chance that I will meet some of the transplant golf people again before the next Transplant Games. And there is a chance I will meet the transplant footballers at the next [football] tournament. Wherever those two occur, I will go to it. I got a car. I am happy to travel anywhere.

Overall, family-focused networks were well connected and relatively dense. These types of networks also represented the most actors perceived as very close and this type of network was stable between phase 1 and phase 3.

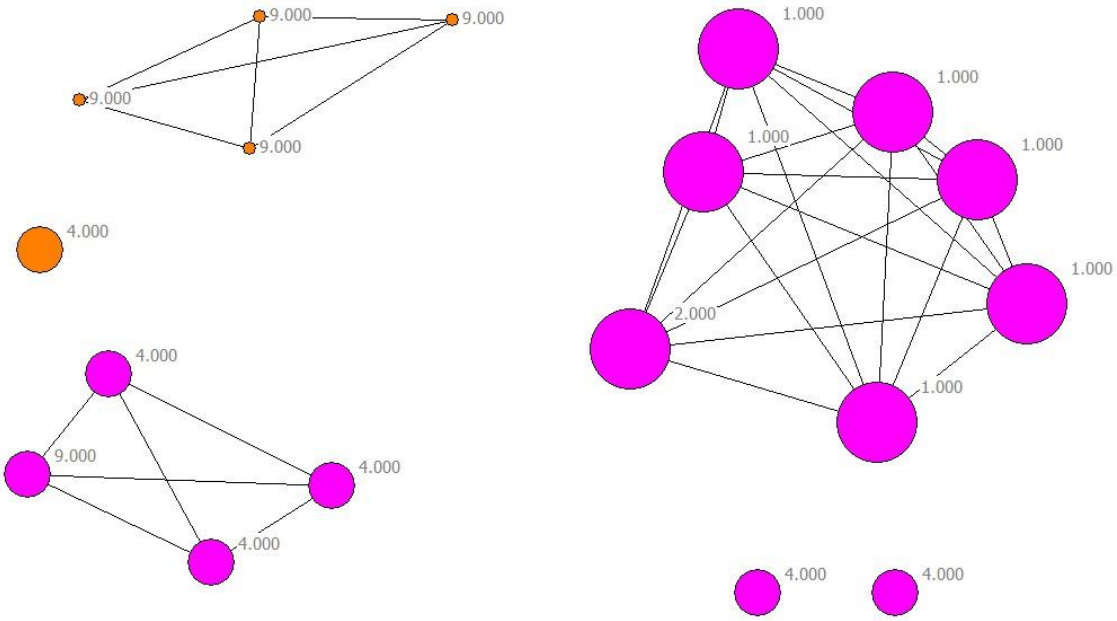


Figure 4.1 Jeffry's family-focused network at phase 1. Node colour: Pink= very close, orange= somewhat close. Node size: large= very close, medium= somewhat close, small= less close. Node shape: circle= no involvement in Transplant Games, square= involvement in Transplant Games. Node label: 1=close family, 2= spouse/partner, 4= friend, 9= organisation or club.

4.4.2 Friend-focused networks

Friend-focused networks consisted of majority friends, outnumbering other types of actors within a network. Further, these friendship actors are considered and perceived as very close. Three participants (Lauren, Joseph, Silvie) had friend-focused networks across phase 1. Lauren's network contained two main regions which included mostly friend actors which were perceived as very close. Within Lauren's network she had perceived her parents as the least close and positioned them furthest away. Within Joseph's network he had one core region which consisted of friend actors with several isolated friend actors distributed throughout the rest of his network. Similarly, Silvie had one core region which included her friend actors. For Silvie, some of her friend actors that demonstrated healthy behaviours had been included within her core region whereas others who demonstrated unhealthy behaviours had been positioned towards the periphery of her network. This sense was captured in the way she spoke about her friends:

> I say my friends on the inner circle, these are also the friends that like to look after themselves. The reason I split those pink friends with those orange ones here is that a group of friends are not that into exercise at all and they are the longer-term friends, so they tend to be a bit more emotional if that makes sense. They tend to bounce off on what is going on in your life and that sort of thing. So, they are less positive, and these ones we see on a less regular basis through various activities.

For Silvie, although some of her friends demonstrated unhealthy behaviours, they were still important for other types of support such as emotional work. Further, although Silvie regarded certain friends who demonstrated healthy behaviours as important, she was not in as regular contact with these friends.

Across phase 3, five participants (Lauren, Jacquie, Joseph, Silvie, Julia) had friend-focused networks. Jacquie's network consisted of two core friend regions positioned centrally and perceived as very close. The rest of her network was largely scattered with several friend actors operating separate spatial zones as isolates. For Julia, her network was very interconnected with core friend actors bridging the different regions within her network. All the regions within Julia's network contained mostly friend actors.

For Lauren, Joseph and Silvie this remained consistent across their phase 1 and phase 3 networks. Lauren had three core regions which were integrated with friend actors which were again perceived as very close. Joseph's network contained two core regions which were densely connected. One of the regions contained the most friend actors which were all

perceived as very close. Figure 4.2 is an example of a friend-focused network displaying Joseph's phase 3 network containing eight very close friends positioned centrally within his network. Joseph acknowledged his wide-ranging friend-focused network in the way he described these actors. Joseph said:

> My friend [friendship actor] when I am sick, she calls me six times a day. She is a television fitness person who lives in Las Vegas and we have been friends for like 20 years. I have friends on a very wide spectrum. I have friends that are very rich and famous, and I have friends that are public servants. I have friends that live on social security and can barely get by. I have friends from all walks of life, and I am very blessed with that.

This extract from Joseph's final interview supports the friend-focus of his network as he outlined the different contact and support, he would receive from a variety of friends. Although his friends were from diverse backgrounds positioned in various locations, they were largely all connected to each other represented as a dense core region. However, for two participants (Jacquie & Julia) their network had changed from a family-friend-focused network to friend-focused network. Overall, participants' friend-focused networks remained stable in terms of the perceived closeness participants attributed to the actors and where these actors were positioned between phase 1 and phase 3.

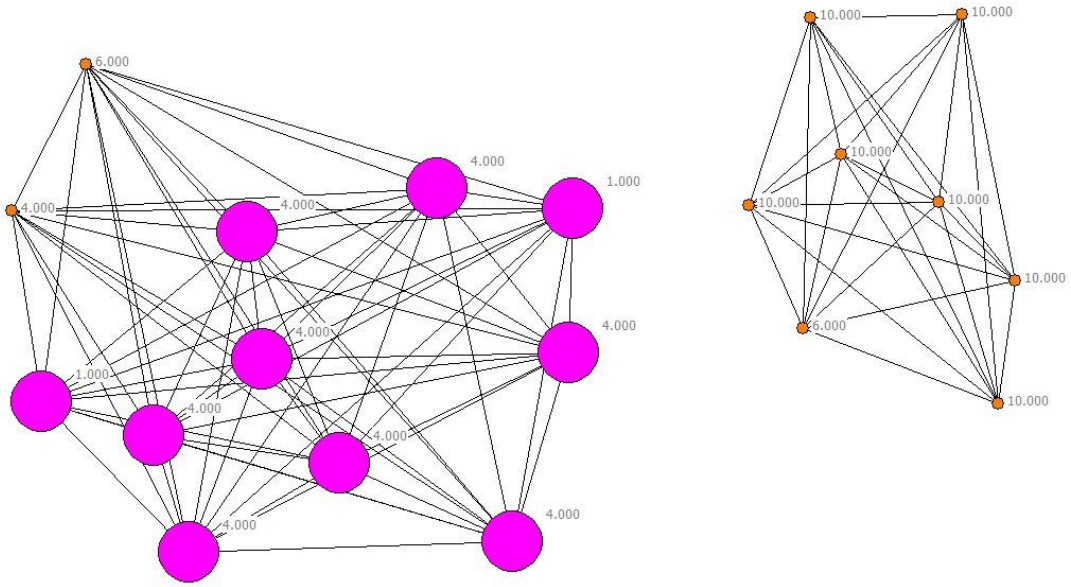


Figure 4.2 Joseph's friend-focused network at phase 3. Node colour: Pink= very close, orange= somewhat close. Node size: large= very close, small= less close. Node shape: circle= no involvement in Transplant Games. Node label: 1=close family, 4= friend, 6= medical practitioner, 10= Transplant Games.

4.4.3 Family-friend-focused networks

Family-friend-focused networks consisted of an equal number of close family and friendship actors where participants networks could not be classified as solely family-focused or friend-focused. The friends and family actors were either represented in separate regions or were integrated within the same regions within participants networks. Across all participants, four (Daniel, Jacquie, Julia, Paulo) had family-friend-focused networks at phase 1. For Paulo, he discussed how he was close to both his family and his friends and how some friends became more involved in his social network when he became ill and throughout his transplantation journey. He said, "I am close with my family, and my closest friend". For Paulo, he felt as though his network became stronger after he was diagnosed with Leukaemia as friends became closer. However, Paulo's family remained very close and were considered stable actors within his network. Similarly, for Julia, her family and friends had become closer after she became ill. When talking about her friends and family Julia stated:

> It all brought us together closer and I think one of the reasons was that none of them wanted to see me die. And they kind of saw me as an incredibly brave person to go through what I had to and then coming through the other end like I did. And like they all really enjoy having me around. Even when I was talking to [friend actor] last night, she reminded me what I had gone through.

Figure 4.3 is an example of a family-friend-focused network which contains an equal number of close family actors and friendship actors within Julia's network at phase 1. These actors are all perceived as very close. For Julia here, her network reflected the way she described the support she received from her family and friends with equal weighting.

Across phase 3, three participants (Daniel, Ella, Jeffry) had family-friend-focused networks. For Daniel, this was consistent across both phases whereby his family actors and friend actors were integrated within the same regions, perceived as very close and positioned centrally. Ella's family-friend focused network included different regions which consisted of either just friend actors or these were integrated with family actors which were perceived as very close. For Jeffry, his network operated different spatial zones which included a friend region and a family-friend region.

Overall, friends and family were perceived as equally important within this type of participants' illness self-management networks. However, this network type was the least consistent type over time.

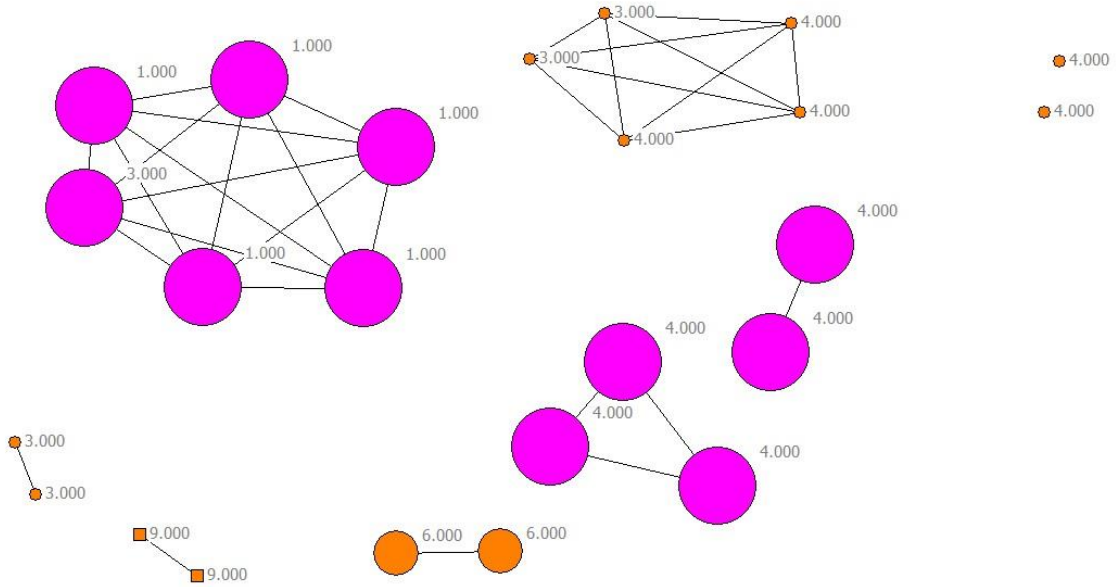


Figure 4.3 Julia's network at phase 1. Node colour: Pink= very close, orange= somewhat close. Node size: large= very close, small= less close. Node shape: circle= no involvement in Transplant Games, square= involvement in Transplant Games. Node label: 1=close family, 4= friend, 6= medical practitioner, 10= Transplant Games.

4.4.4 Diverse-sport-focused networks

The diverse-sport-focused networks consisted of a combination of Transplant Games actors, family, friends, work colleagues, medical practitioners, and organisations. These types of actors were perceived as either very or somewhat close with the majority positioned centrally. Five participants (Robert, Ella, Toby, Brian, Courtney) had diverse sport-focused networks at phase 1. For Courtney and Robert, they had positioned Transplant Games actors centrally, perceived as very close (large sized actor). For these participants, their Transplant Games actors were strong connections which promoted their perceived closeness. Courtney described how her badminton partner had become part of her very close support network:

> My badminton partner would be the second closest. The Transplant Games are like another family. Like you do not see them as much, but you have the tournaments and whatever and it is nice to see them. You have good chats and stuff like this.

The proximity of other Transplant Games members within participants networks signified the perceived importance of these members that participants shared experiences and multiple identities with. Toby discussed the impact of the Games on his personal social network. He stated:

> Yeah, my network has changed, I have on here, 5 that are just from the volleyball team that through the British and the World Games I have got to know. I look at them and they inspire me, one friend has had a transplant for 30 years and she is so inspiring you know. It just really helped me. I say looking at it [network] more people are on it than last year. There is one guy in there I know just through royal Liverpool [football] team who was also at the worlds. There is a lot more there, I think when we first chatted it would have been mainly just football.

Participants gained Transplant Games members which became central to their personal social networks. As participants moved towards health and typically positioned their identities away from being ill, they gained network members that embodied health and self-management practices.

For Brian, Toby and Ella, the placement of their Transplant Games actors was considered as somewhat close. Ella had a diverse-sport-focused network at phase 1 and a family-friend-focused network at phase 3. For Brian, he had become less connected to the Transplant Games and perceived these actors as less close which is visually seen when comparing his phase 1 and phase 3 networks. Brian attributed this change from diverse-sport focused network to family-focused network to assuming a sense of normality as he discussed during his phase 3 interview. Brian stated:

> I mean I think partly the last 12 months I have concentrated on being normal. And I think I needed to do that which has meant that sort of my, while I was engaged at a distance on social media in terms of fellow transplant recipients. I feel a bit less connected into the whole Transplant Sport network but only really because I have taken a bit of a back seat on it and actually, I just needed to focus on other stuff this year which has been good.

Brian's decision to step back from Transplant Games impacted on how he perceived the closeness of Transplant Games actors represented within his network. In Brian's case, these actors remained part of his network but became less central to his day-to-day life and illness self-management which promoted these actors towards the peripheries.

Robert, Toby, and Courtney had diverse-sport-focused networks at phase 3. For these three participants, Transplant Games actors were prominent within their networks. Figure 4.4 is an example of Robert's diverse-sport-focused network containing several Transplant Games actors, close family actors and medical practitioners perceived as very close and somewhat close. A few of Robert's Transplant Games actors were perceived as very close, centrally positioned. This demonstrates that Transplant Games actors were considered important to Robert's illness self-management, several months after competing in Transplant Games events for the first time.

Overall, participants discussed how the Transplant Games actors included within their networks acted as an 'extended' or 'additional' family which would assume that it offered support that participants perceived as important, similar to the support perceived and received from family members. This helps evidence the way in which participants sought support from network members that were less close than family which helps to demonstrate the impact participating in Transplant Games events for the first time has on participants' illness self-management networks.

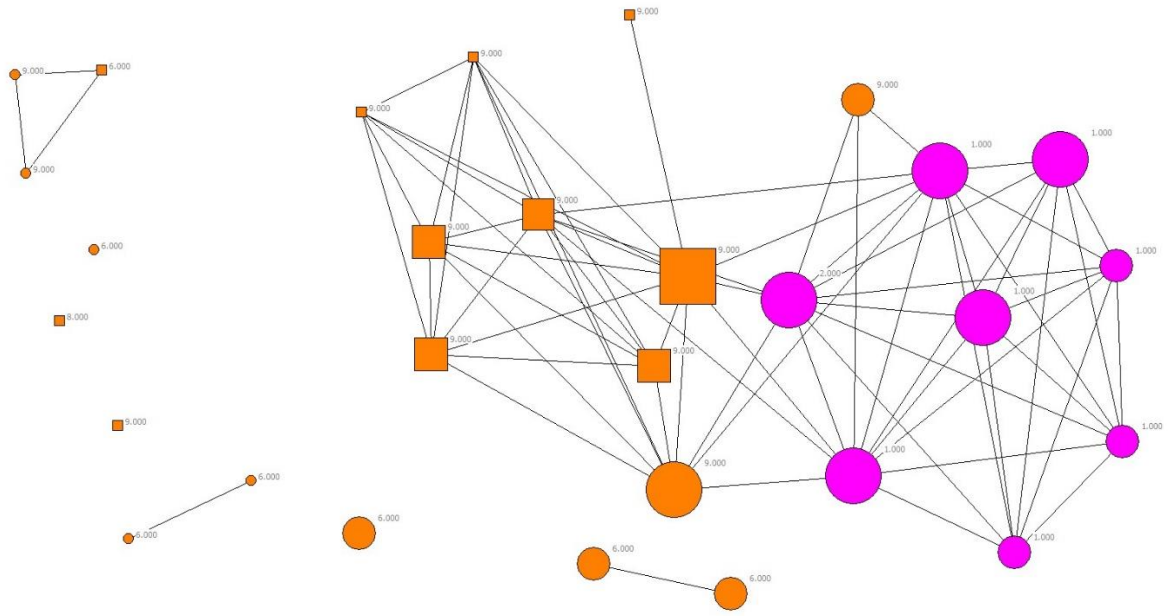


Figure 4.4 Robert's diverse-sport-focused network at phase 3. Node colour: Pink= very close, orange= somewhat close. Node size: large= very close, small= less close. Node shape: circle= no involvement in Transplant Games, square= involvement in Transplant Games. Node label: 1=close family, 4= friend, 6= medical practitioner, 10= Transplant Games.

4.5 Summary

Within this chapter, I have outlined the characteristics of participants illness self-management networks having participated in Transplant Games events for the first time. This included the size of networks and the types of relationships and support considered important within participants' networks. The purpose of this was to determine how illness self-management networks were represented and how participating in the Transplant Games for the first time influenced the size, relationships, type of support and types of networks. I found that Transplant Games actors did not influence the overall network types unless the Transplant Games actors were perceived as very close. Furthermore, most participants had represented either family-focused or friend-focused networks and these two network types were most stable over time. The diverse-sport focused networks represented Transplant Games actors perceived as very close, centrally positioned within the network, and connected to a variety of other actors. Although participant network types help to establish the overall characteristics of illness self-management networks, further analysis is required to understand structural change across networks and how this is impacted by participating in Transplant Games events for the first time. Therefore, the next chapter will offer results of the visual network analysis which considers the micro level structures over time.

CHAPTER 5: LONGITUDINAL CHANGES IN ILLNESS SELF-MANAGEMENT NETWORKS

5.1 Introduction

Building on from the characteristics of illness self-management networks identified in the previous chapter, this chapter will present the longitudinal changes in illness self-management networks. I will address the following research question; *'How do the illness self-management networks of transplant recipients who have participated in Transplant Games events for the first time change over the 12-months following participation?'*. I will present the visual network analysis where I investigate and report on the regions, centres, density, interfaces, and infrastructure of participants' social networks to better understand how the structural dimensions of networks are shaped through participating in Transplant Games events over time. I will use interview data from the phase 1 and phase 3 interviews to support the visual network analysis and provide further context and meaning. Decuypere (2020) stated that, "analysing the form of a network likewise only makes sense if one continuously oscillates between the visual characteristics (topological dimensions) of the network and the contextual information that was gathered during previous steps of interviewing" (Decuypere, 2020, p. 84). In this way, the interview data helps me to describe the actors and ties. It also offers detailed justifications about the actors and ties, and at times, gives participants' explanations of why change has occurred. I will outline each topological dimension in turn, providing interview data to offer further depth. This will be supported by several visualisations of participants' social networks as examples to illuminate change throughout each topological dimension.

5.2 Regions

5.2.1 Reminder of rationale

The proximity and closeness of regions within networks can be used to help understand the influence of the Transplant Games regions within participants' social networks. Further, discovering the shifting and dynamic nature of Transplant Games regions over time may be useful for making inferences about the impact of participating in Transplant Games events for the first time. Further, this may illuminate how taking part impacts participants' illness self-management networks over time. Regions consist of a concentration of actors that interact within a given network. Actors that interact with each other are positioned closer together, creating bounded spaces within a network. It is these bounded spaces that influence on an

individual's behaviours (Carrington, Scott, & Wasserman, 2005). Transplant Games regions present within participants' networks may influence illness self-management behaviours. Specifically, across participants' social networks, Transplant Games regions may offer various support for illness self-management.

5.2.2 Findings

Across phase 1, the regions within participants' networks were largely varied with Daniel's network containing the fewest (one region) and Ella's network containing the most (seven regions). Across all participants' networks, nine did not have specific Transplant Games regions within their networks. However, out of these nine participants, four participants had either isolated or dyadic relationships representing Transplant Games actors. Here, the Transplant Games actors were not integrated within the rest of the network and were usually positioned on the peripheries of participants' networks. The remaining six participants (Robert, Claire, Ella, Michael, Toby, Brian) had Transplant Games regions within their networks. For Robert, most actors within his Transplant Games region were perceived as very close with only a few perceived as less close. Similarly, for Ella, this region was perceived as somewhat close. Ella discussed how helpful and important her Transplant Games region was to her self-management. She explained:

> This [region] is the Transplant Games curling team from the World Games. There is [actor 1], [actor 2] and [actor 3], then I put in [actor 4] from the transplant team because she is quite an influential person to know and is quite helpful and important. And then I have got [actor 5] and [actor 6] who were also part of my post-transplant support group. So, we have had a lot of tears and a lot of discussions and they are really helpful in understanding what we were trying to do, and everyone is getting to grips with medication and self-management.

Ella reviewed the separate regions she had within her network, some of which consisted of her Transplant Games actors which formed her curling teammates. Ella discussed the importance of this region within her network when it came to "getting to grips" with self-management. Through participating in Transplant Games events, regions were formed in participants' networks as they shared experiences with similar others interested in being active through sport which created connections. However, Ella's Transplant Games region was perceived as less close than other regions within her network. Furthermore, the Transplant Games region was not included within her phase 3 network.

Most participants' Transplant Games region had lessened in importance by phase 3. However, some participants had made lasting strong ties with actors within these regions which then became part of other regions within the network such as close family or friend regions. Across phase 3, ten participants did not have any Transplant Games regions. Although for six participants (Lauren, Claire, Ella, Jacquie, Jeffry, Courtney), they had isolated, dyadic relationships, or Transplant Games actors integrated within other regions. For the remaining six participants (Robert, Michael, Toby, Brian, Julia, Paulo), each had a dedicated Transplant Games region within their network. For Michael, this region was positioned on the peripheries of his network, considered less close compared to other regions. Although this region remained consistently positioned as less close within his network over time, it became less connected to the rest of his network. This was reflected in how he spoke about the placement of Transplant Games actors within his network. Michael said:

> I will put these out on the periphery because they are Transplant Gamers, I only see them at the Games, another group of friends over here who I only see once in a while, they don't know anyone else… So, my network is going to get bigger as well. The indoor football group are a whole new set of lads.

Here, Michael determines the closeness of his Transplant Games actors based on how much contact he has with them. In this case, they remained on the peripheries as seen in Figure 5.1. However, this region remained within his network across both phases supporting the way Michael used sport and the maintenance of his Transplant Games region as a way of positioning a stable healthy sense of self. Here, the Transplant Games actors remained part of participants' networks as a future focus on competing in the Games again.

Another example that best illustrates this is Toby, whose network consisted of a Transplant Games region across both phases (see Figure 5.2). At phase 1, his Transplant Games region consisted of eleven Transplant Games actors perceived as somewhat close. At phase 3, Toby's Transplant Games region had reduced in size from eleven actors to four actors. However, the four Transplant Games actors now representing this region were perceived as very close which had become well connected with Toby's core family network. Toby determined this region as his friends rather than Transplant Games contacts as presented within his phase 1 network. In a lengthy extract, Toby stated:

> Yeah, it has now I have 4 [Transplant Games actors] that are just from the volleyball team that through the British and the World Transplant Games I have got to know. There is one guy there I know just through Royal Liverpool team who was also at the Worlds. I look at them and they inspire me, one friend has had a transplant for 30 years

> and she is so inspiring you know- it just really helped me. I say looking at it more people are on it than last year and the whole volleyball team- we had all bonded. The reason they were not on here [network map] last time was that they were already a team when I came in, so I felt like a bit of an outsider.

Although Toby spoke about having several more Transplant Games actors important to his illness self-management since his first Transplant Games, he had fewer actors represented within his phase 3 network as seen in Figure 5.2. Here lies a contradiction in how Toby perceived his network and what was represented within his network. Instead of more Transplant Games actors, the few actors Toby had placed within his network were perceived as closer. This may have led to the perception that he had a bigger Transplant Games region due to the significant influence this region had on his illness self-management as he became closer to them.

Overall, participants' networks displayed several different regions across both phases over the 12-month study duration. Transplant Games actors were represented as either separate regions or they were integrated within other regions which held various relationships. Further, some participants' networks displayed isolated, dyadic Transplant Games actors which were not part of any regions. Over time, the Transplant Games regions either became integrated within other core regions (see Figure 5.2), or these regions diminished on to the peripheries of networks, operating as separate spatial zones (see Figure 5.1). The significance of these findings is twofold. Firstly, as Transplant Games regions may influence behaviour, the perceived importance and place of these regions within a participants' network may influence illness self-management or may influence participants' continued participation in Transplant Games events. Further, the Transplant Games actors situated on the peripheries may also provide significant support as weaker ties.

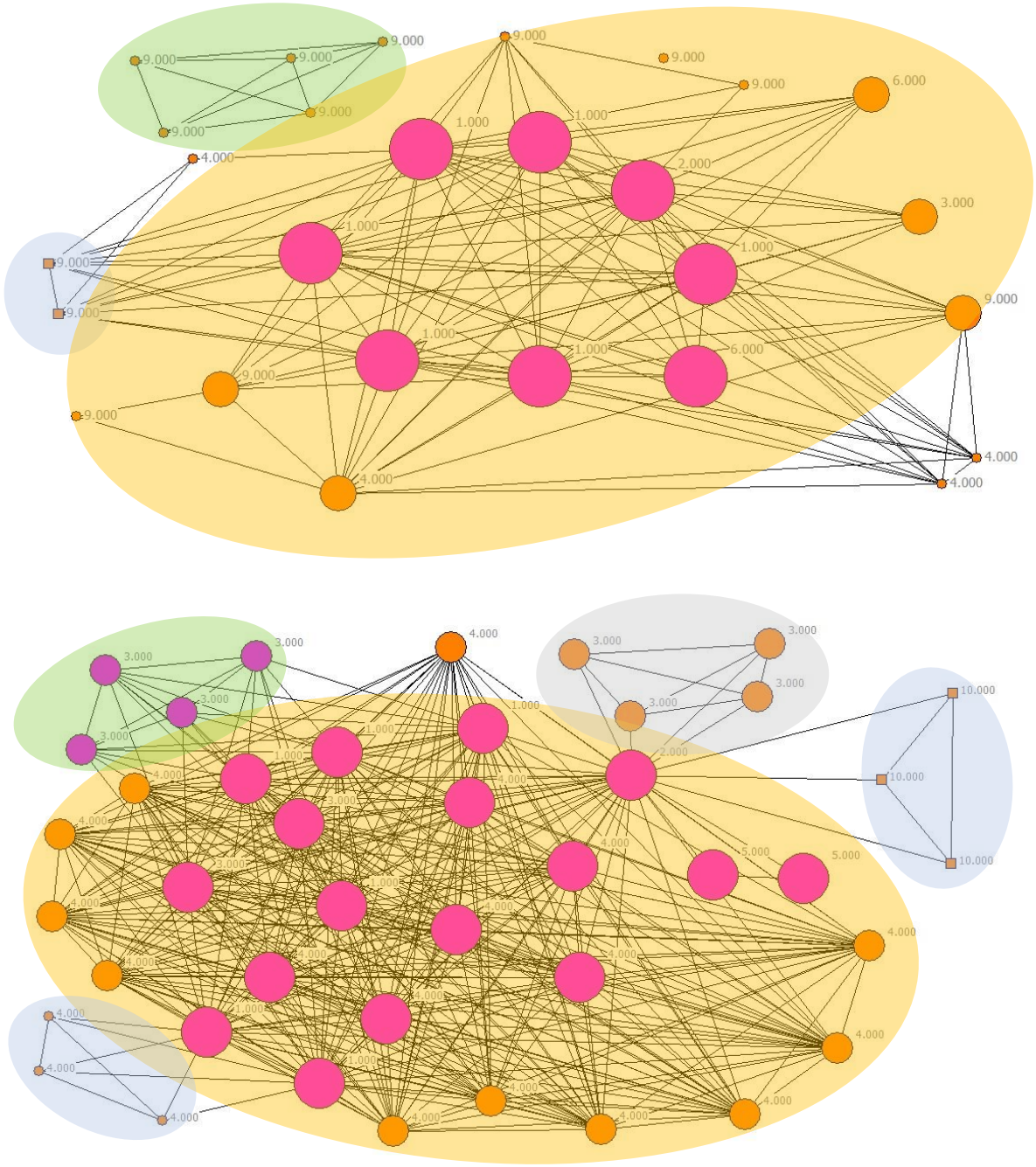


Figure 5.1 Michael's network at phase 1 (top) and phase 3 (bottom) displaying multiple regions and periphery Transplant Games region. Node colour: Pink= very close, orange= somewhat close. Node size: large= very close, medium= somewhat close, small= less close. Node shape: circle= no involvement in Transplant Games, square= involvement in Transplant Games. Node label: 1=close family, 2= spouse/partner, 4= friend, 5= work colleague, 6= medical practitioner, 9= organisation or club.

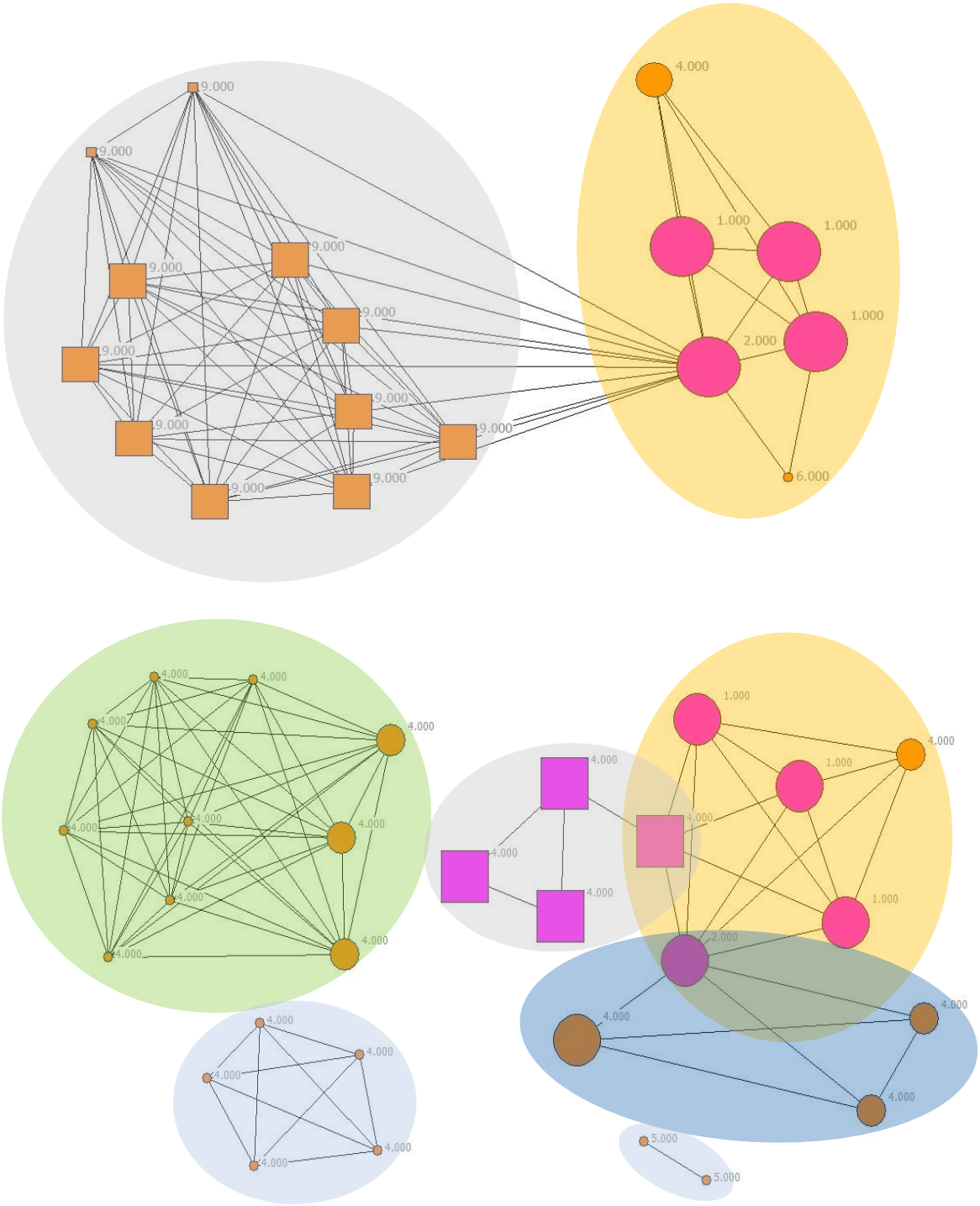


Figure 5.2 Toby's network at phase 1 (top) and phase 3 (bottom) depicting Transplant Games region becoming very close. Node colour: Pink= very close, orange= somewhat close. Node size: large= very close, medium= somewhat close, small= less close. Node shape: circle= no involvement in Transplant Games, square= involvement in Transplant Games. Node label: 1=close family, 2= spouse/partner, 4= friend, 5= work colleague, 6= medical practitioner, 9= organisation or club.

5.3 Centres

5.3.1 Reminder of rationale

Having determined the specific Transplant Games regions within participants' networks, I now turn attention to actors which hold central positions within participants' networks. Centres represent actors which are heavily interconnected within a region or within a whole network. Therefore, centres hold a position of authority and prominence given the central role they play (O'Malley & Marsden, 2008). The purpose of this section is to understand whether Transplant Games actors hold central positions which would further demonstrate the impact participating in the Games has on participants' social networks. Central actors can visually be seen within a network often represented in a star-like form, connected to several other actors (Decuypere, 2020).

5.3.2 Findings

Nine participants (Anika, Robert, Claire, Daniel, Michael, Silvie, Toby, Courtney, Paulo) had positioned their spouse or partner centrally within their networks during phase 1. This was consistent with how participants spoke about their spouse or partner as being very important and central to their illness self-management. Claire stated, "my husband and my kids are centre circle. It is all about family for me. I can't put it into words really, they have just supported me through everything". Similarly, Jacquie discussed why her husband was central within her network, "I mean my husband gave up everything this year so he could train me, he is a cyclist anyway". Despite the central importance of spouses displayed within most networks during phase 1, only three participants (Anika, Robert, Toby) spouse or partner held a central position within their network at phase 3. For most participants, their networks either became more integrated or new actors were added creating separate worlds with less central actors.

For Daniel, his wife did not hold a central position within his phase 3 network which can be explained by the way he spoke of the difficulties in his relationship (see Figure 5.3). When asked who Daniel considered as the most important members within his network, he stated:

> So, my wife is obviously important because she is my wife but we have a breakdown in communication recently but that is starting to resolve itself now. So, she has been more and less important I would say within the last year or so. There are certain things

> that I just have not told her because things have been strange because of the illness really. So that is a bit complicated. She was the first closest one really but at times not.

Here, Daniel's wife held a less central role within his network over time and was not connected to his weaker ties with which he sought illness and emotional work from as he moved towards illness again. Here, Daniel positions his network towards illness again which encourages the strength of weaker ties. This became apparent as he discussed how he withheld information about his health from his wife to reduce her anxiety. This highlights the dynamic nature of participants' networks as actors weave in and out of closeness and proximity within participants' networks. This was articulated as Daniel discussed how his wife was "the first closest one really but at times not". However, this was not always reflected in the networks themselves. Without the interview data the dynamic nature of the networks would not be as clearly seen. Further, in support for the importance of weaker ties within a network, Daniel discussed how an isolated actor provided emotional work:

> They are not really from the same social circle. [Friend 4] is the best in terms of she just lets me complain about my life, which I think that is what I need in my life sometimes. I just need to complain how awful it is sometimes and as I say I think my mum and my wife are caught up in their own problems and their feelings of anxiety that they find it very difficult.

Here, Daniel receives emotional work from an actor positioned further away from his core region, a weaker tie in terms of connectedness and proximity to other network actors.

For most participants, their spouse or partner was still perceived as very close within their networks and were usually the first network members to be placed within their networks. Further, how participants spoke about the anxiety presented when discussing their health with very close actors did not impact the perceived importance of these actors. Instead, it promoted other actors less close which became more central over time.

In some instances, Transplant Games actors also held central positions. For example, Robert and Toby both had Transplant Games actors holding central positions across their networks at phase 1 and phase 3, respectively. These actors were deemed very close across both their networks. For Robert, he discussed the importance of two of his central Transplant Games actors which represented his team manager and another team member he interacted with in a meaningful way. Robert stated:

> He [team manager] is considerably closer to me than my wife is at times. And [team member] is as well. She and [team manager] are very close to my family. He [team manager] has been one of the most instrumental people in my life. He would probably

> grab you and tell you how good his team was, he is a very positive lovely bloke, a great guy. He is a superb team manager.

This is coherent with the structure of Robert's phase 1 network seen in Figure 5.4. Here, we can visually see two actors (orange squares) which represent Transplant Games actors with whom Robert had met through participating in the Transplant Games and were positioned centrally within his network. Across both networks over time, these actors remained central within Roberts network close to his core family region.

Overall, most participants' networks were largely interconnected in which central actors bridged the gap between regions. However, these central actors often represented participants' spouse or partner and as such no overarching patterns of Transplant Games actors could be established across all participants' networks over time. That said, in some cases, Transplant Games actors were also positioned centrally, although these actors were often perceived as very close and integrated with other regions such as close family and friends. What can be established from this finding is that although Transplant Games actors may be perceived as close and important to illness self-management, these actors do not need to hold central roles within the network to be influential.

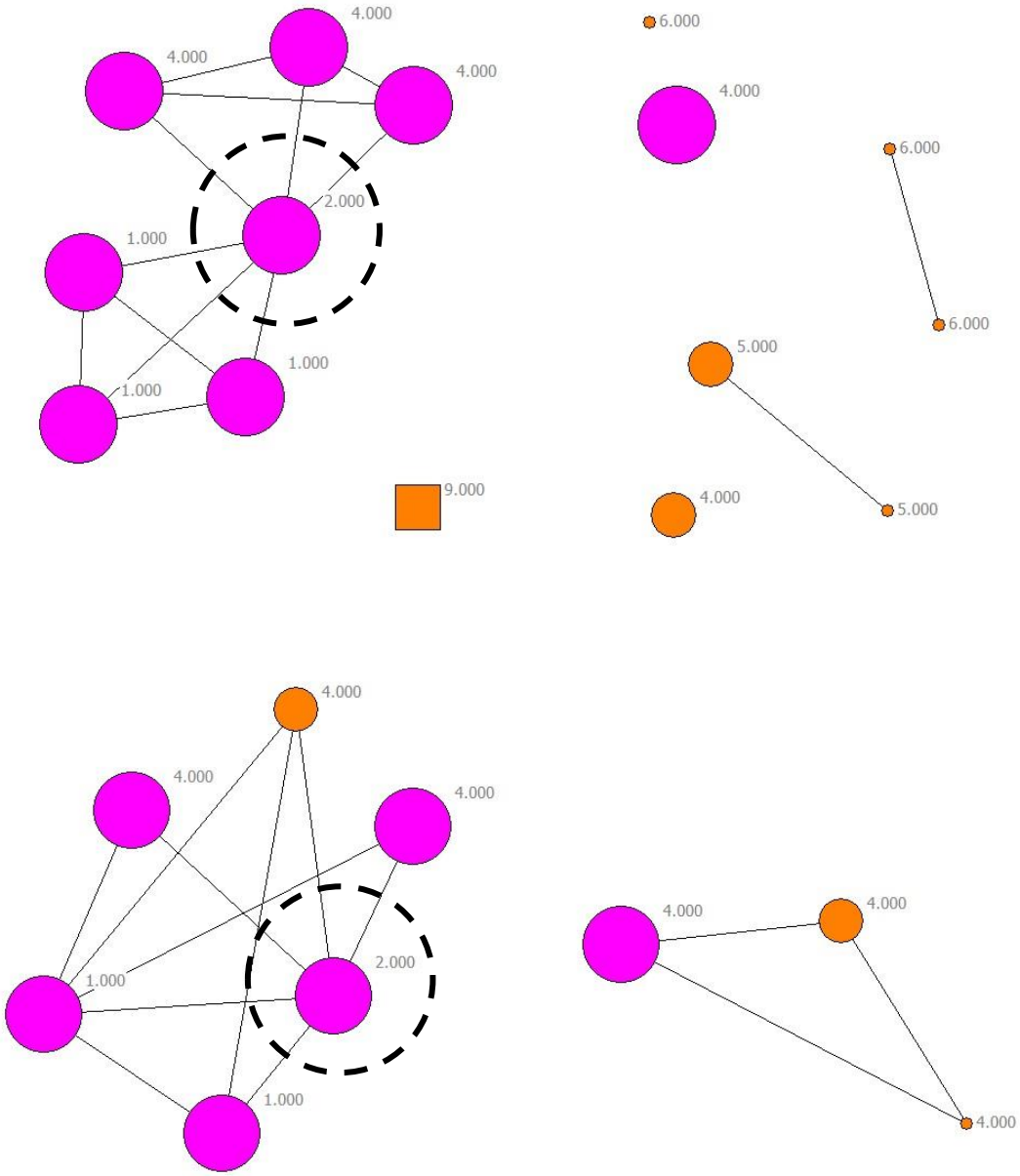


Figure 5.3 Daniel's network at phase 1 (top) with spouse positioned centrally and phase 3 (bottom) without spouse as centre within very close region. Node colour: Pink= very close, orange= somewhat close. Node size: large= very close, medium= somewhat close, small= less close. Node shape: circle= no involvement in Transplant Games, square= involvement in Transplant Games. Node label: 1=close family, 2= spouse/partner, 4= friend, 5= work colleague, 6= medical practitioner, 9= organisation or club.

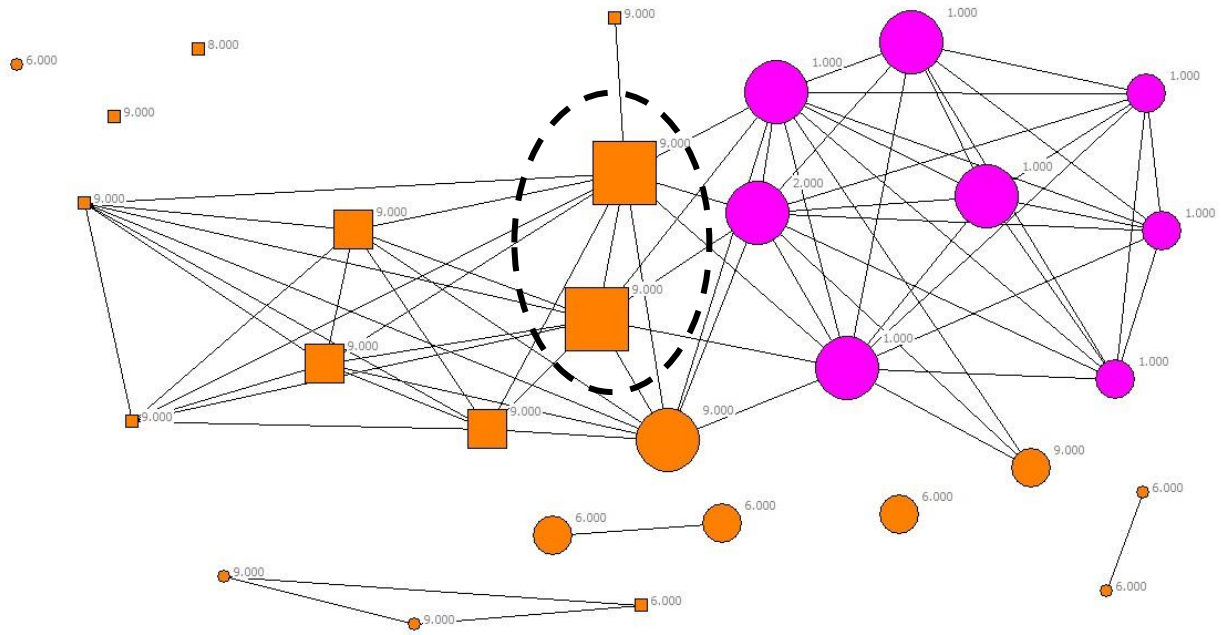


Figure 5.4 Robert's network at phase 1 displaying central Transplant Games actors. Node colour: Pink= very close, orange= somewhat close. Node size: large= very close, medium= somewhat close, small= less close. Node shape: circle= no involvement in Transplant Games, square= involvement in Transplant Games. Node label: 1=close family, 2= spouse/partner, 4= friend, 5= work colleague, 6= medical practitioner, 8= someone online, 9= organisation or club.

5.4 Density

5.4.1 Reminder of rationale

Density refers to the interconnectedness of actors within a region or network. According to a number of studies, if a network or specific region is very dense it implies that multiple actors need to be mobilized to perform an activity and that the specific region or network is cohesive (Venturini, Jacomy, & Jensen, 2019; Venturini, Jacomy, & Pereira, 2014). The implications for participants in this study is that activity mobilised through densely populated regions or a whole network could impact on their illness self-management and the continuation of active health behaviours. Furthermore, Transplant Games actors within a densely populated region or network may influence participation in the Transplant Games. Therefore, density may be a useful measure in determining the impact of Transplant Games events over time.

5.4.2 Findings

Across both phase 1 and 3 over the 12-month study duration, most participants had relatively dense networks, of whom several participants had separate worlds or regions operating distinct yet well connected spatial zones within their networks over time. For example, as seen in Figure 5.5, Claire's core region which contained her very close actors remained very dense across her network at phase 1 and phase 3, yet separate and less connected to other regions. The density of Claire's core region can be further explained in the way Claire discussed her closest contacts. She stated:

> Well, they all know each other, well the ones that are immediate to each other. like we all know each other. Like my family, my husband's family, and our family. My circles are not quite… circles.

Here, Claire discussed how her core network was made up of different circles that had become integrated into one core family region. At phase 3 Claire had observed a similar level of connectedness within her very close core region containing spouse, close family, extended family, and friends. Here Claire stated, "my circle kind of hasn't changed that much because I think maybe I am a very open person and I am very friendly and everything, but I keep my inner circle very close". Despite Claire's network remaining very dense, her Transplant Games actors within her network did not become integrated within her different regions within her network over time. These actors remained as a separate region perceived as less close. However, these weaker contacts were still important to Claire and her illness self-management.

We know that through weak ties, important information is shared within a network. Claire went on to discuss the importance of these weaker ties as she explained her relationship with one Transplant Games actor specifically. Claire stated:

> I am lucky in that sense as one of the girls, another one that was transplanted a little bit after me she is a former athlete. She's awesome, but I can see what she is doing and if she can do it and she is transplanted then that's inspiring to me you know… and she is local so she is at the other end of the phone, you know we have gone for walks together so we have chatted, she is a support, we have the same thing in common in that we are both kidney transplant recipients you know.

Despite the importance Claire attributes to this Transplant Games actor in terms of providing support, this actor remains positioned away from her core regions, perceived as the least close within her network.

Conversely, Courtney who had relatively less dense network across phase 1 and 3, had Transplant Games actors positioned as isolates, separate from the rest of her network at phase 1. However, somewhat different to Claire's network, these actors became integrated within her network over time as seen in her phase 3 network (see Figure 5.6). For Courtney, these Transplant Games actors represented her badminton partner and a transplant recipient who she had met through the Transplant Games and become friends with. Both actors were perceived as very close to Courtney over time. During the phase 1 interview Courtney stated, "so apart from my badminton partner and transplant friend everyone is connected… So yeah, I have a very connected circle". Here, Courtney acknowledged her isolated Transplant Games actors which did not share connections with the rest of her network. This may in part be due to the how these actors had only recently become part of her network, having competed in the Transplant Games for the first time. What we can understand from this insight is that despite the perceived importance and closeness of actors, in this case the Transplant Games actors, they did become interconnected. Therefore, the network could not be assumed as cohesive and as such, behaviours mobilised and shared within a network may differ between actors. However, during the phase 3 interview Courtney reflected on how they had become integrated as she discussed her closeness with her badminton partner which can be seen visually in Figure 5.6. She stated:

> My badminton partner would be the second closest. She had to play down the age group because there is no one that could play the age group I am, and she is quite good at it as well. You become very close, unbelievably close and we are so alike we have similar hobbies and I have met her family and her kids, boys, her husband, and we are now arranging a weekend together so that is really amazing actually yeah.

Over time, these Transplant Games actors had become embedded in Courtney's network. However, a point of difference between Courtney's and Claire's network is that for Courtney these Transplant Games actors were perceived as very close throughout phase 1 and phase 3. However, this did not significantly impact on the density of Courtney's network which remained relatively dense over time. For Claire, her Transplant Games actors remained less close over time which influenced the lack of density within her network. Here, the new actors included did not become integrated or influence the density of the network.

Overall, participants' networks maintained relatively dense within specific regions. That is, the actors within a given region held multiple connections with each other. This would suggest that for a given activity to be performed, multiple actors would need to be mobilised to carry out this activity. The implication of the density of specific regions within participants' network regions is that these actors may significantly contribute to the actions of participants' post-transplant outcomes such as illness self-management behaviours. Furthermore, isolated, and weaker ties that were positioned outside of the densely populated regions, in some cases became imbedded within participants' network over time. For some participants, the weaker ties that remained less close and disconnected from the rest of the network still provided support and were considered important to participants' illness self-management.

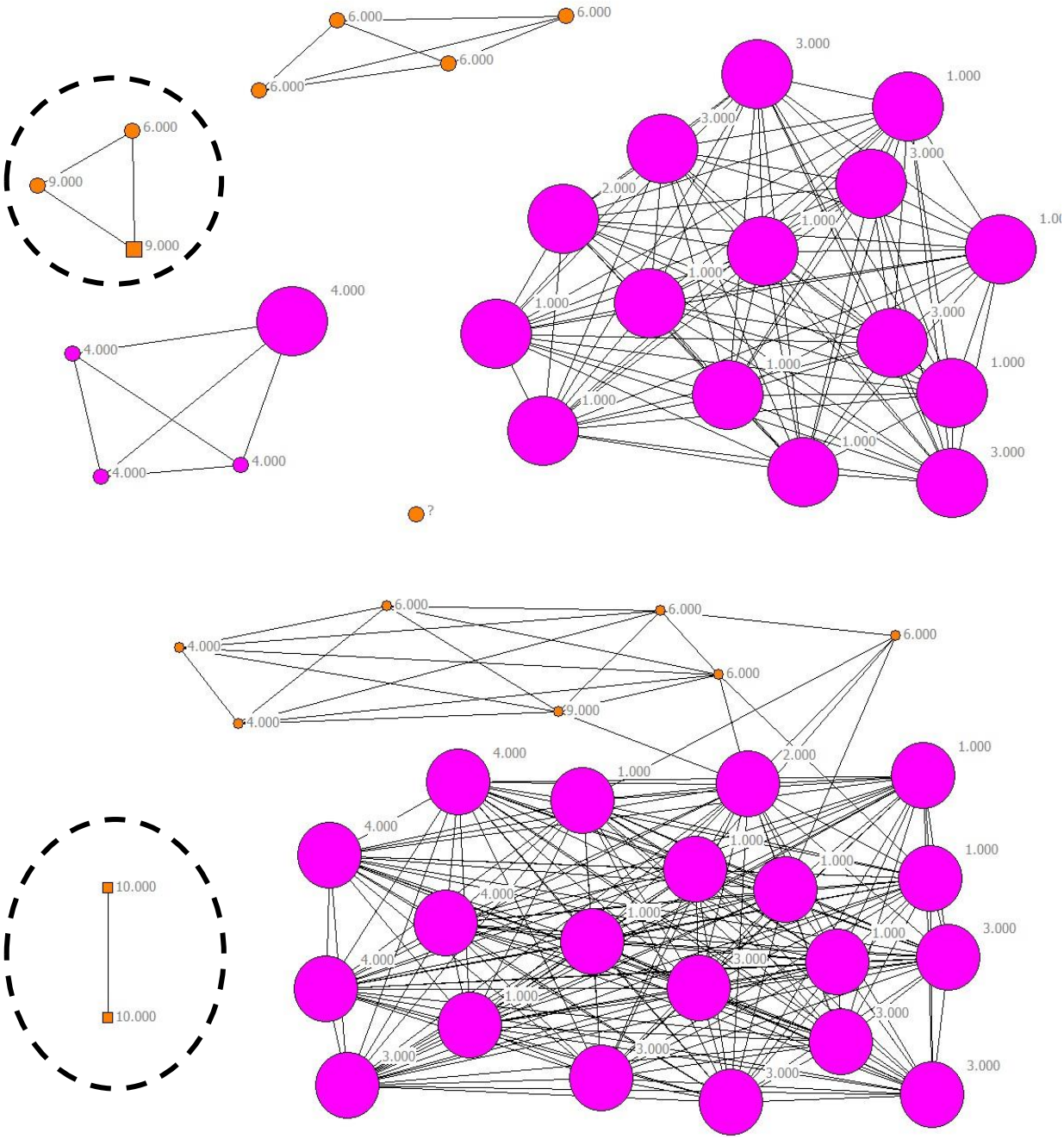


Figure 5.5 Claire's network at phase 1 (top) and phase 3 (bottom) demonstrating density of core region and isolated Transplant Games alters. Node colour: Pink= very close, orange= somewhat close. Node size: large= very close, medium= somewhat close, small= less close. Node shape: circle= no involvement in Transplant Games, square= involvement in Transplant Games. Node label: 1=close family, 2= spouse/partner, 3=extended family 4= friend, 6= medical practitioner, 9= organisation or club, 10= Transplant Games, ?=unknown.

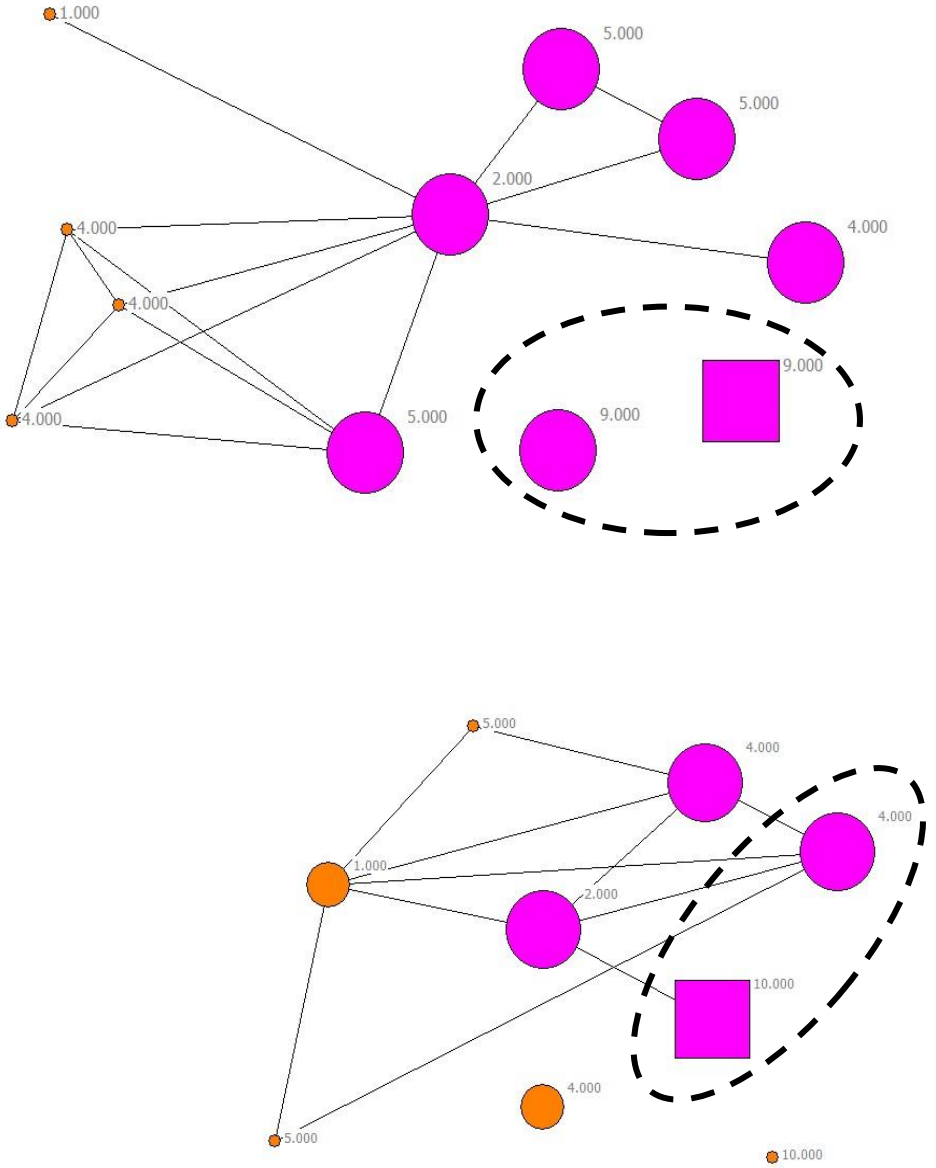


Figure 5.6 Courtney's network at phase 1 (top) and phase 3 (bottom) demonstrating the integration of Transplant Games actors over time. Node colour: Pink= very close, orange= somewhat close. Node size: large= very close, medium= somewhat close, small= less close. Node shape: circle= no involvement in Transplant Games, square= involvement in Transplant Games. Node label: 1=close family, 2= spouse/partner, 4= friend, 5= work colleague, 6= medical practitioner, 9= organisation or club, 10= Transplant Games.

5.5 Interfaces

5.5.1 Reminder of rationale

Interfaces refer to areas of overlap between different regions within a network. Actors that are positioned between different regions hold boundary positions which make regions permeable. In line with the social network concept of brokerage, boundary actors have the potential to be in more than one region at a time which affords them a level of importance in carrying out different activities within a network (Gould & Fernandez, 1989). Boundary actors perform as relays as they can be associated with unifying different parts of a network enabling connection and communication between regions (Prell, 2012). Of interest here, is how Transplant Games actors are situated within participants' networks and if they act as interfaces between regions.

5.5.2 Findings

Across phase 1, most participants had no overlap between different regions within their networks, therefore, no boundary positions could be assumed across these networks. Instead, participants had spatially distinct zones within their network. Across phase 3, most participants again had no overlap between regions and therefore no boundary actors within their network. Six participants (Anika, Daniel, Jacquie, Jeffry, Joseph, Brian) social networks remained largely dispersed over 12-month duration between their phase 1 and phase 3 networks which was perceived positively. For example, Figure 5.7 displays Brian's network across the 12-month study which had no bridging actors and his Transplant Games actors formed separate regions not connected to other regions within his network. Brian made sense of this in how he compartmentalised his network in terms of managing transplant outcomes. He stated:

> The disease could be managed pretty much within the family, we did not need to, other than people just generally being kind of understanding you know, I did not really have a big network of people outside giving direct close support.

Brian discussed how his close family would provide support for managing his transplant and how he did not require support from other groups or regions within his network. Brian rationalised these separate worlds within his network positively over time. When reflecting on his phase 3 network he said:

> I do not feel isolated but when you look at it, I feel quite self-sufficient in a sense. I feel a bit less connected into the whole Transplant Sport network but only really because I have taken a bit of a back seat on it and actually, I just needed to focus on other stuff

> this year and which has been good. I feel like they are the normal arms-length social media sort of relationships. It can be fairly sporadic and fairly intermittent, but you know and its quite passive, I would not pretend to have any real degree of closeness other than we have something in common and generally they are mostly the cyclists.

The implications of this suggest that perceived importance influences the positioning of actors and regions within a network.

Conversely, both Michael and Julia had several boundary actors and overlapping regions displayed within their networks across phase 3. For example, Julia's network demonstrated the most change in terms of interfaces across both phases (see Figure 5.8). Julia's phase 1 network displayed several regions acting as separate worlds with no interfaces connecting them. Distinctions can be made between the way Julia discusses the different support she received from her network over time and what can be seen visually within Figure 5.8. Julia describes the various support she received throughout illness and transplantation that is important to her illness self-management which she included within her network. She stated:

> I will start with my two sisters, they came to look after me during my transplant and they made it happen regarding organising people to come and look after me, it was about sharing the load, then [two] nursing friends they came and helped me. And then [two other friends], they came up for week 2 and they've kind of help me heal, they are always there for me, and we do lots of things together, they live close by, my sisters do not live close by, but we are in regular contact. Then another friend, he did not help me with the transplant, but he has always given me a lot of time regarding cycling, and he came to the Australian Transplant Games with me just as a social support and that was really good.

This extract from Julia's phase 1 interview highlights the different support she had received throughout her transplant journey and the separate regions which provided support at various times. Conversely, Julia's phase 1 network did not contain separate regions providing different types of support at the same time, these separate worlds were constructed over time and were called on for different support at times which she perceived certain support to be important. Although, these regions did not contain any interfaces or actors holding boundary positions.

Julia's network at phase 3 contained several interfaces connecting separate regions together. Julia attributed this to having "a good network of friends". Julia's network here demonstrated a shared interest in her sporting capabilities and achievements which reinforces the role of boundary actors within a network. Julia stated:

> It is interesting at my work, how occupied my colleagues were with these Games. Even the doctors that I worked with, the intensive carer [boundary friendship actor] he was

> really interested in the Games and never had heard of them. I have an old nursing group and they are friends I have had for 20 years and I also have my cycling group.

Julia reflected on the shared interest between her different social worlds which could be due to the role the boundary actors played within her network. Here, Julia's different regions in her network shared a common interest in her participation in the Transplant Games. Further, Julia discussed how one actor was situated between two worlds which had become closer over time as contact with him increased. She stated, "I might just shift one [actor] of those over because he is part of that world as well, but I see a lot of him... so he is a bit closer". This supports the widely accepted notion that boundary actors are afforded with more importance promoting their proximity and closeness within a network over time.

Overall, most participants maintained separate worlds with no boundary actors present across their networks. Others either had boundary actors interfacing between regions which represented a variety of relationship types, or they had a commonly shared interest or behaviour that connected them. This was true for Julia where it was the shared interest in her participation in the Transplant Games that could be assumed to have connected regions within her network at phase 3. Although the separate worlds within participants' networks evidence the different types of support participants had received and perceived as important throughout the 12-month study duration, in most cases across participants' networks, Transplant Games actors remained as separate worlds and were not connected to other regions through interfaces. That said, this was largely determined based on how close participants perceived these Transplant Games actors. Participants who perceived these as very close or somewhat close were positioned more centrally, connected to other regions. Those Transplant Games actors perceived as less close were situated and remained on the peripheries over time. However, this was likely to be reciprocally influential as actors that held a boundary position were more likely perceived to be closer and actors perceived closer would share more connections within a network.

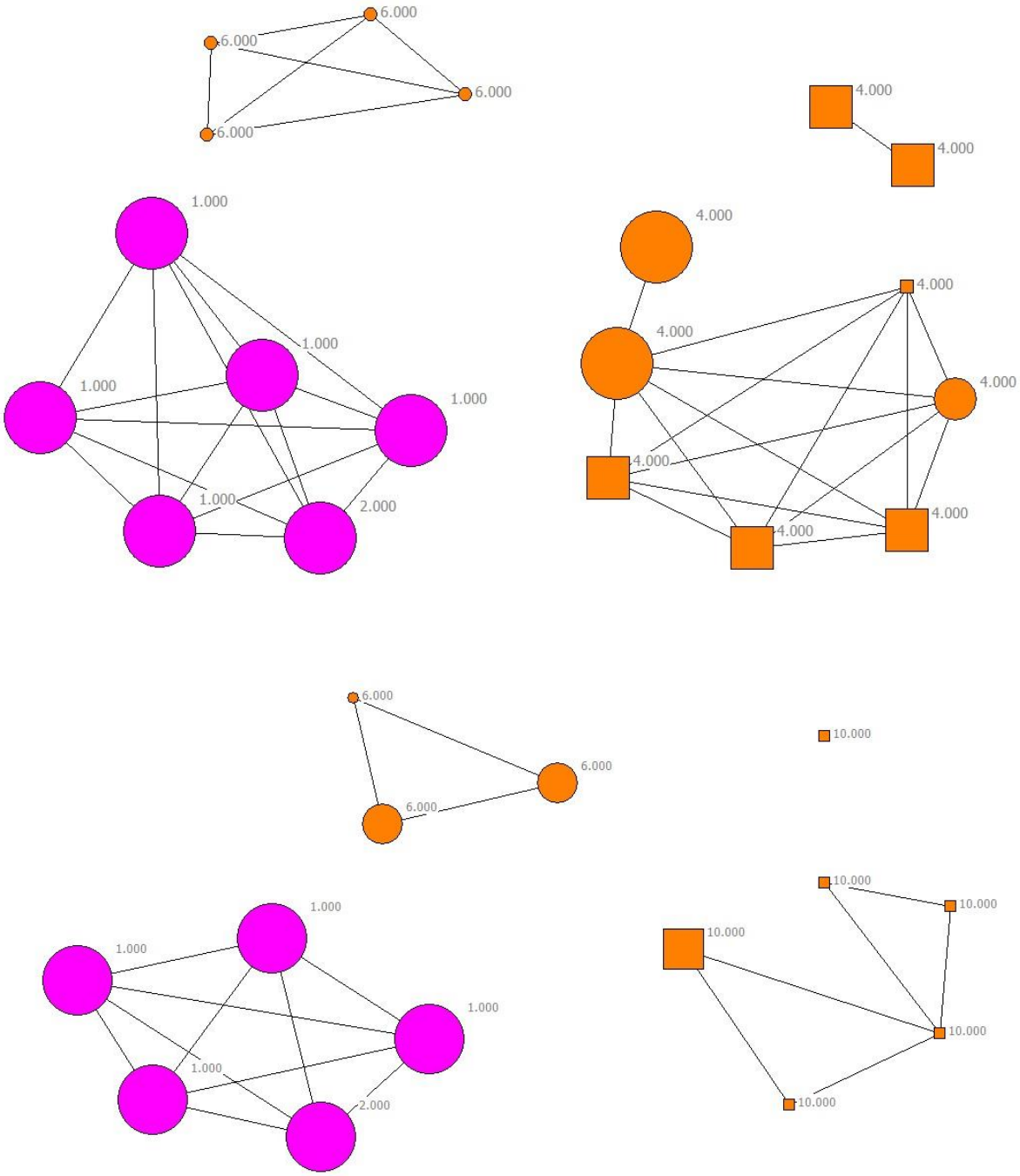
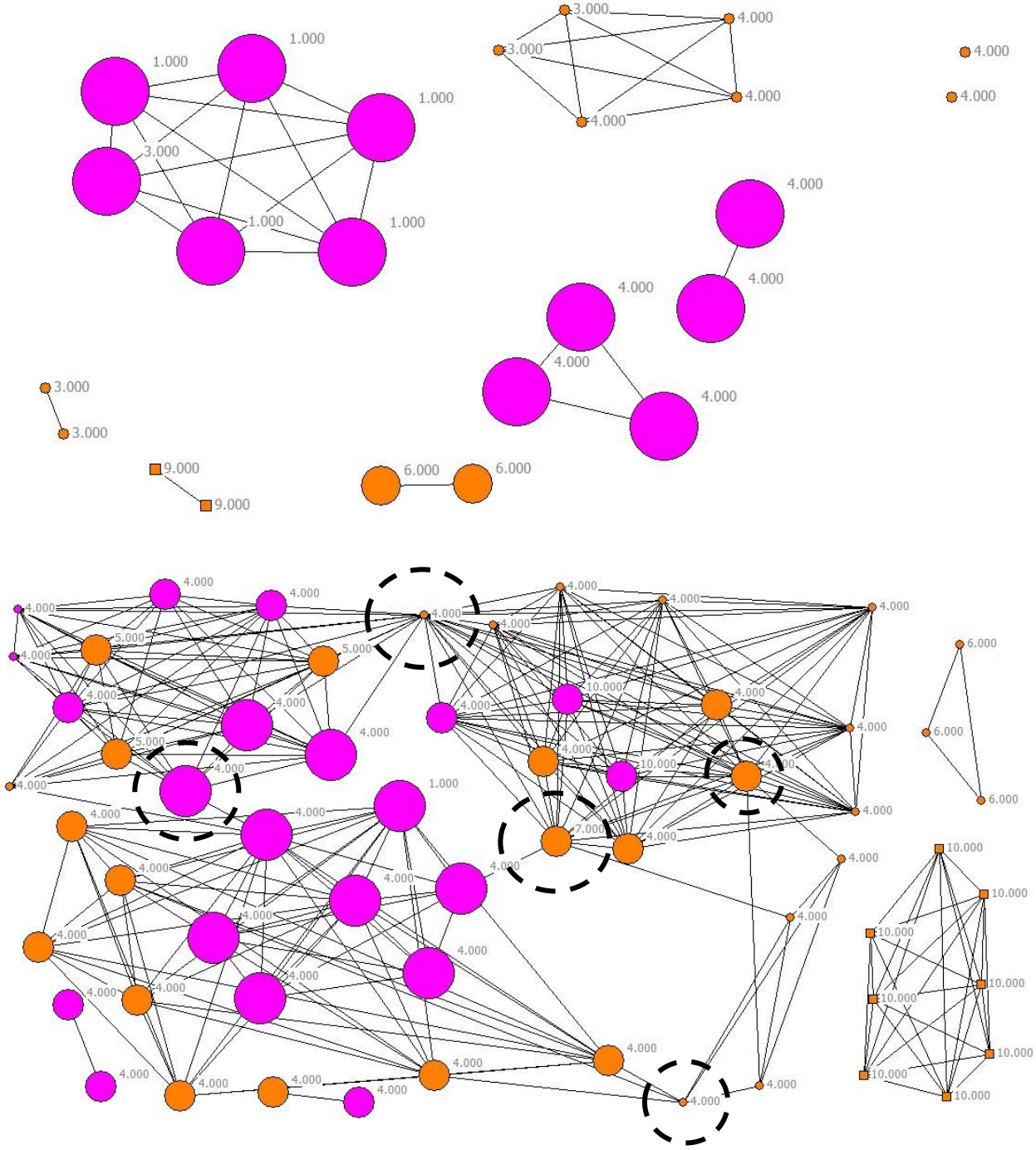


Figure 5.7 Brian's phase 1 (top) and phase 3 (bottom) network displaying separate worlds and no boundary actors. Node colour: Pink= very close, orange= somewhat close. Node size: large= very close, medium= somewhat close, small= less close. Node shape: circle= no involvement in Transplant Games, square= involvement in Transplant Games. Node label: 1=close family, 2= spouse/partner, 4= friend, 6= medical practitioner, 10= Transplant Games.


1.000
1.000
1.000
3.000
1.000
1.000
3.000
4.000
4.000
4.000
3.000
4.000
4.000
4.000
4.000
4.000
4.000
3.000
3.000
9.000
9.000
6.000
6.000
4.000
4.000
4.000
4.000
4.000
4

5.6 Infrastructure

5.6.1 Reminder of rationale

The infrastructure of a network refers to the types of actors within a network which specifically allows for analysing certain types of actors which populate specific regions within a network. Within this final topological dimension, I will investigate the Transplant Games actors included within participants' networks and the positioning of these actors within regions. Understanding the influence of Transplant Games actors on participants' networks will help to determine whether these actors may impact on participants' illness management. The infrastructure of participants' networks will focus specifically on the Transplant Games actors included within the networks.

5.6.2 Findings

A total of 14 out of 16 participants had included Transplant Games actors met through participating in the Transplant Games within their network at either phase 1 or phase 3. However, for two participants (Silvie and Anika), they did not include any Transplant Games actors within any of their networks over time. For Silvie, she felt as though the Transplant Games represented a level of disability with which she did not identify with. She stated, "I think the fix of my kidney is something to me where I would not classify myself as disabled and I felt that the Games still had an element of that sort of persona". For Silvie, as seen in her network over time (see Figure 5.9), she did not identify with the Transplant Games or as a transplant recipient as she moved away from illness due to the 'fix of her kidney'. This statement provides a rationale for why there are no Transplant Games actors included within her network at phase 1 and phase 3.

There was a total of 35 Transplant Games actors included within participants' phase 1 networks. Out of the 35 actors, three were considered very close, 19 were positioned within the middle circle, considered somewhat close and 13 were positioned the furthest away as least close. Three participants had only included Transplant Games actors within their phase 1 social network. Across phase 3, there was a total of 39 actors across all participants' networks met through participating in the Transplant Games. From this, two alters were considered very close, positioned in the centre circle, five actors were considered somewhat close and 32 perceived as less close positioned within the outer circle of participants' social networks. Five

participants had Transplant Games actors only included within their phase 3 network having none placed within their phase 1 networks. Between phase 1 and phase 3, Transplant Games actors became less close as 32 out of 39 of these actors included within participants networks at phase 3 were positioned furthest away within the less close category.

Overall, the infrastructure of participants' networks was largely varied. For most participants, attending Transplant Games events for the first time impacted their illness self-management networks through the inclusion of actors met through the Games. Furthermore, whilst Transplant Games actors were included in most participants' networks these were perceived as less close than other actors and often positioned on the peripheries of participants' networks. The Transplant Games actors continued to be placed within participants networks over 12-months. The implications of this finding are that although these actors were perceived as less close, they were still influential and perceived as important to illness self-management in the way that participants spoke about them within the interviews. This finding provides support for the network concept of the strength of weak ties (Granovetter, 1977). Finally, although only two participants had no Transplant Games actors represented in their networks after participating in the Games, it may be possible that if future competitors did not identify or positively perceive the Games and the influence of other competitors, then their illness self-management networks may not be impacted from their one-off involvement. This may have implications on prolonged engagement in Transplant Games events and for obtaining the possible positive effects on individuals' networks such as the role of Transplant Games actors in supporting illness self-management.

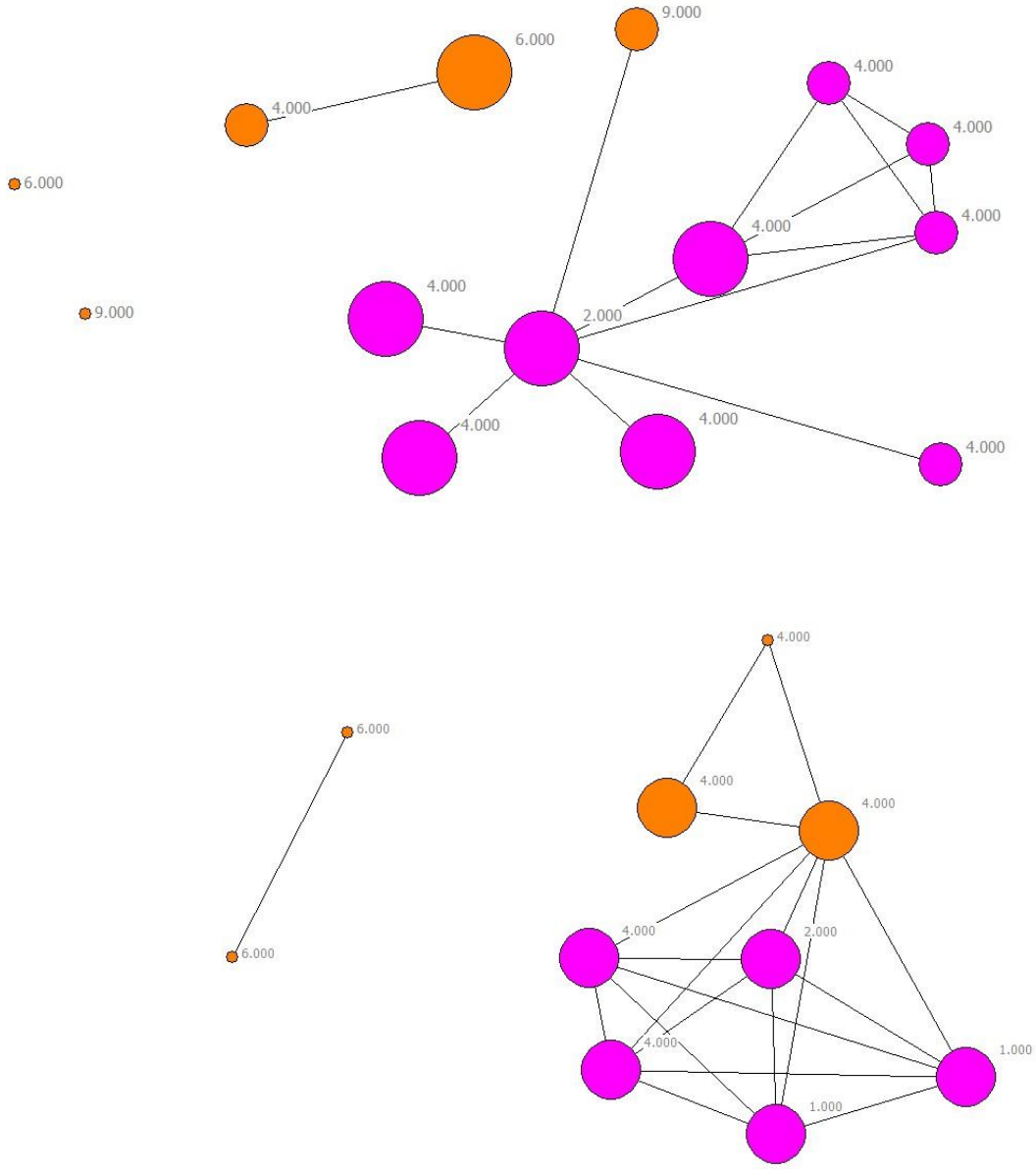


Figure 5.9 Silvie's phase 1 (top) and phase 3 (bottom) network displaying no Transplant Games actors over time. Node colour: Pink= very close, orange= somewhat close. Node size: large= very close, medium= somewhat close, small= less close. Node shape: circle= no involvement in Transplant Games. Node label: 1=close family, 2= spouse/partner, 4= friend, 6= medical practitioner, 9= organisation or club.

5.7 Summary

Within this chapter I have outlined the structural changes in participants' social ties over time. Using visual network analysis, I identified the impact of Transplant Games actors on participants' illness self-management networks across the topological dimensions including the regions, centres, density, interfaces, and infrastructure. Furthermore, in combining the visual interpretations of participant social network with the interview data from phase 1 and phase 3 interviews, I have illuminated how participants spoke about and made sense of their networks over time. Within the next chapter, I will present the experiential aspects of illness self-management networks which consists of a thematic analysis of the interview data.

CHAPTER 6: EXPERIENTIAL ASPECTS OF ILLNESS SELF-MANAGEMENT NETWORKS

6.1 Introduction

Within this chapter I present a thematic analysis of the 48 interview transcripts from all 16 participants. This chapter addresses the following research question; '*Why does taking part in Transplant Games events impact illness self-management networks?*' The interview transcripts were analysed using inductive thematic analysis which produced four main themes. Each theme offers an explanation into how taking part in Transplant Games events impacted on participants' illness self-management networks.

The first theme, *close tie anxiety,* details participants' experiences of the anxiety and worry their close support network endured throughout their illness and transplant trajectory. This encouraged the agency of weaker ties, promoted through taking part in Transplant Games events who were called on for illness and emotional work. The second theme, *automatic propinquity,* considers how closeness and relatedness between transplant recipients became realised through shared experiences of similar illnesses. Here, competing in Transplant Games events reinforced the closeness between recipients as they shared similar interests and identities as a transplant athlete. The third theme, *negotiating transliminality through sport,* explores how participants constructed their experiences of health and illness through participating in Transplant Games events. Participants re-examined the extent to which they felt in-between being healthy and ill as they participated in Transplant Games events which impacted on their illness self-management networks. The fourth theme, *gratitude, survivors' guilt, and obligation to pay it forward* reflects participants appreciation for a second chance at life. This includes feelings of survivors' guilt for being kept alive which influenced participants notions of giving something back through raising awareness and taking part in Transplant Games events. Here, gratitude spread through Transplant Games contacts which influenced illness self-management networks and future behaviour. Each theme will be discussed in turn supported with evidence from all interview transcripts across the 12-month study duration.

6.2 Close tie anxiety

Taking part in Transplant Games events impacted on participants' illness self-management networks as participants looked for ways of managing the negative emotional responses experienced from their close support network. Participation in Transplant Games events often

promoted weaker ties which became established in participants' illness self-management networks, alleviating the pressures on close ties in offering types of work.

The close support network members in participants' personal networks, usually immediate family, spouse, or partners had experienced mental scars through witnessing the illness and transplantation trajectories of their loved ones. For Robert, he attributed this to his mental health struggles throughout his illness and transplantation journey. He said, "I had encephalopathy for so long. And at the end of it, it was devastatingly debilitating. Not in a physical way but in a mental way". This had a significant impact on Robert's family as he recalled how this was something he was still managing. Robert stated:

> Constant anger and confusion and just plain meanness really dominated my family life. We all got the physical scars, everyone around us has matching mental scars. So, we are still dealing with in some cases. Certainly, with my children, with the aftermath of growing up because my son cannot remember me before my transplant being healthy, my daughter can. So, for the first few years of his life all my son could remember was having this very, very ill father who just shouted at him a lot and that takes a lot of getting over.

It was the "mental scars" that Robert stressed would take significant time to get over, despite moving towards improved health post-transplant. Furthermore, it is about the nature of close relationships which had become part of the management process post-transplant. Here, Robert differentiated his own illness and transplant experiences to that of his close family. In this case, his family were still dealing with the "aftermath" of Robert's illness.

Similarly, Daniel (also a liver transplant recipient) reflects on how his family also experienced emotional distress throughout the transplant, "my family suffered so much because of my liver transplant". Here, Daniel attributes this suffering to his liver transplant separating his own experiences to those of his family. This was commonly seen within the analysis across all participants. Participants had distinguished between their own experiences and the experiences of their close family as being different. Participants reported how, for their families, it was more difficult to comprehend, given their lack of control over the situation. Ella narrates this well as she recalls the experience of heart failure as she was going into labour with twins:

> It was worse for them [family] because they had to watch. I could not do anything I was stuck in a bed. They were having to sort of deal with things because when I arrived at the hospital for heart failure, I must admit I do not think I quite understood what was going on, because I think I was a wee bit out of it. But that day when my husband arrived, and mum and dad were there, and mother-in-law and father-in-law were there

> as well. They [doctors] basically told the family to prepare themselves that none of the three of us would survive… Or the kids might be okay, and I might not be, or I might be okay the kids might not be. So, you know, I think that still plays heavily in their minds.

The magnitude of this experience for her family was considerable, which caused a significant level of distress and trauma throughout her social network. Here, her close support network had been most affected due to the proximity of the relationships as they witnessed first-hand the rapid decline in Ella's health. For Ella, post-transplant fluctuations in her health would trigger the memories or mental scars of this experience for her family, which would generate panic and unease over her health. Ella stated:

> I think they start to go into a panic mode of 'oh my god what happens if you are not okay, do you need to go to the hospital?' 'What are we going to do?' 'How are we going to juggle everything, what does this mean?' Sometimes it's a bit like I am generally just tired, or the kids have had a cold all week. It's not surprising I am a bit sniffy. You know so it's really, they do they just panic. Even like my husband still worries. He panics about it more than me. You know if I say 'ahhhh I am feeling a bit-tired today'. He's like 'urhh are you okay…?!' I am like 'I am tired I am busy at work and we have two small people you know', its life.

Here, Ella's understanding of her own health and her limits post-transplant is not something that is shared with her close family network as they are constantly reminded of the fragility of her health when she experiences minor concerns such as the common cold. There remains a disconnect between participants' first-hand experiences and the experiences of people in their close support network. It appears that the proximity of social support impacted on the mental scars experienced. That is, those network members closest to the participants at the time of illness, experienced negative emotional responses post-transplant. Furthermore, across all the participants it was close family that experienced the mental scars and emotional stress more so than the participants themselves. As Jeffry recalled:

> It was much worse for my wife. I am sure she was under much more stress than I was. Because I really did not have a choice and I think that is a pretty common scenario is that the patient is under less stress. I could do things about it. I could manage my case, and just try and stay as healthy as I could. Whereas the families and friends they really cannot do much except worry.

In conjunction with notions of emotional distress and mental scars experienced by close family networks, from recalling experiences of chronic illness and transplantation, anxiety and worry presented itself in daily interactions with close family members. Numerous examples of participants expressing how their close family and close network members experienced anxiety and worry were identified within the interviews. Paulo described how his family shared anxiety

about his health. He said, “a lot of the feelings are the same as the anxiety, the hope experienced between life and death, these kinds of things are very similar. Yeah, mainly the closest people, I think they share the same feelings and same worries”. For Paulo, his closest support network all shared feelings of worry regarding his health. For Joseph, he felt his close friendship network had become distant. He said, “they [close friends] want to be my friend from a distance, but they don’t necessarily want me in their home at a party, that’s what I think”. Here, Joseph felt that his close support network was cautious of his health which reduced their contact with Joseph himself.

Similarly, Daniel discussed how people within his close support network were impacted by his health daily, which they struggled to cope with. He stated, “there was a lot of worry about me constantly”. He goes on to explain his mother’s worry and anxiety in that, “she is very concerned about my health of course she is, but she can’t, she can’t really cope with those feelings of anxiety, I almost feel like she brings this to me”. Here, Daniel expresses concern for anxiety experienced by his close family network which ultimately impacted on him.

The anxiety and worry that participants witnessed in their close family often limited the way they interacted with them about their health. Participants noted how they would often hold back information regarding their health to reduce the worry and anxiety that this may cause. An example of this was observed in comments made by Daniel, again, who said:

> To be honest I do not tell her [mum] everything because she cannot hack it. So, I suppose what I am saying is that I tell her what I think she can cope with. But again, I have not told my mum because there is no certainty. I mean obviously if I go on the list, I am going to have to tell her of course I will. But I cannot say to her oh they are thinking about assessing me for transplantation again because she cannot deal with that level of uncertainty, she will just lose her mind. I have to say I wasn’t going to tell my wife at all, because we had lots of relationship difficulties relating to all the stuff that has happened when I was ill so the only reason why I told her was because I just thought that if I don’t tell her that’s just me basically just scrapping the whole marriage, that’s me giving up.

Participants would hold back sharing developments regarding their health. In this way, some participants first decided if it is appropriate to share with close support network as part of a sense making process before deciding how to share this information with close family support network.

Courtney described in length, the difficulties in sharing her health concerns with her partner. For Courtney, her partner was too emotionally close which required her to provide support in the form of ongoing reassurances that she was healthy. Courtney described:

> So, there was a sense that my partner - she was around and everything and she was more like, she tried to be very helpful [Laughs] but she was more emotionally sort of involved. She was like, 'ah, you are having a transplant', and I'm like 'yeah I am but calm down' and she was in a bit of a panic state and she was crying, and I was like 'oh my god'. I had to actually reassure her, and it was actually me who needed that. It is better for you to actually focus on yourself.

Similarly, for Claire, she described how her family was too close to deal with her health concerns. She stated:

> I actually think it is probably too close, I'm too close to them so they couldn't actually deal with it which is a strange concept I know but it was almost like the only way they could cope was just to pretend that there was nothing wrong you know… Emotionally and everything when I was busy trying to survive, I suppose they [close family] were there for my parents and essentially at the end of the day, that's all I wanted was to make sure my parents were okay through this you know really. So, they did do what they needed to do in being there for my parents.

Participants would filter the information that they were told regarding their health from the medical staff and would only present part of the story to their close family network to reduce anxiety and worry experienced. This was because the close family members would influence the participants' own anxiety levels. Therefore, participants managed the worry and anxiety of their close support network which became integrated in their self-management practices. Further, this promoted the strength in weaker ties that would be called on to provide support when participants wanted to discuss their transplant concerns.

Through participation in Transplant Games events, participants could build a sport-based social network that became a way of managing the close tie anxiety. Here, sport acted as a tool in managing close relationships and building new relationships through weaker ties. These weaker ties provided a buffering effect when discussing health concerns, limiting these future interactions with close support network members. For example, some participants often felt reluctant to share too much information with close contacts as they stressed that these close ties did not understand how they felt promoting weaker ties through participating in Transplant Games events. As Toby recalled:

> You get to a point where you just go, 'well you just haven't got a clue how I feel?' And that is not fair on who you are talking to because they haven't, but they are still doing the best to try and help you. I mean I would not go into full details with them, and there are things that perhaps I wouldn't talk to them about. But I think in talking to my two [Transplant Games] friends, I can talk to them about pretty much anything, and they usually just nod and say 'yup, been there'.

For all the participants in this study, they often shared more information regarding their transplant and general health with other transplant recipients or those who were positioned further away from them emotionally within their social network. That is, through automatic propinquity participants found it easier to discuss their health with individuals who were less emotionally close to the day-to-day management of their health. In some cases, these individuals were other transplant recipients or competitors met through Transplant Games events. In this way, participants found a way of managing the anxiety and worry of their close family network which had become ingrained in their self-management practices. It was drawing support from individuals who were distant enough that they could cope with hearing about ongoing health concerns without inducing levels of anxiety and worry that participants utilised as a way of coping. Thus, participants promoted the strength of weaker ties that could reduce close tie anxiety.

6.3 Automatic propinquity

Connected to the first theme were deeply held meanings and experiences of an immediate bond participants felt with others who shared similar illness and transplantation experiences. Here, taking part in Transplant Games events had an impact on illness self-management networks as these networks were characterised by the way in which participants connected with each other as they reflected on their illness, near-death, and transplant experiences. These experiences were often realised and illuminated through meeting others at Transplant Games events. Jeffry articulates this well as he stated, "it is a bit of a club, a secret handshake kind of thing. We have all been through all the common elements and we have all been almost dead. So that makes it a rather exclusive club". Participants could relate to one another as there existed a shared empathy and compassion established through lived-body experiences. Claire stated:

> There is an instant bond, talking about any chronic disease is important. People radiate to each other if they are open to talking about things like that. Because they say nobody knows your life, no one can understand you unless they have walked in your shoes. There is a mutual respect and the journey that people are on, it is like a knowing. I like to know their stories but there is a mutual respect that you go through hard times.

For Claire, it was the shared understanding of chronic disease which created a bond and a "knowing" between transplant recipients as they embarked on their illness and transplantation journeys.

Similarly, Anika observed a level of understanding of her health and illness with others who had shared experiences. She said, "they know exactly what you mean when you say something, they know exactly how you feel and how the body works and how it makes you… even when you are having an off day… You know they understand what is going on, like the mood swings (laughs)". For Anika, it was a shared understanding that went beyond the physical towards understanding the emotional impact of having a transplant. Here, Anika acknowledges her fluctuating health as novel and specific to transplant recipients that only others who experienced similar experiences would understand.

As participants situated their own future life expectancies, they also developed a sense of longevity in the connections they had made with other transplant recipients. As Claire states, "I know this is for life, so you are always going to need these people". Automatic propinquity was developed as participants moved through their illness trajectories and acknowledged that the management of their health was a life-long responsibility. The life-long management impacted how participants viewed others who had experienced similar illness and transplantation.

Although participants discussed that there existed an instant bond or connection between themselves and other transplant recipients, there was a sense that for some participants this bond was stronger with those who had experienced similar illnesses and the same transplants. Here, this friendship reflects the longevity of chronic illness and transplantation and the need for automatic propinquity. For example, Michael talked about friendship with those who had been through the same cancer treatment as he had. He recalled:

> I have got a best friend who went through similar treatment to me and he was just two months in front of me. We had the same cancer, we had initially the exact same two treatments.

For Michael, this friendship had developed because of the shared experience of cancer and receiving the same stem cell transplant. Similarly, Silvie also discusses how she had formed friendships with other patients who had experienced chronic kidney disease and had received a kidney transplant. Silvie stated:

> I have got two friends who I meet regularly when I go for blood tests and say, 'do you fancy coming', and we will have a catch up over a cup of tea. And it is nice, we do share things that only a patient would know or understand. You sort of have that automatic connection because you know that you have both been through the same

> thing. And you can laugh at the same sort of jokes about kidneys and things without other people being offended.

Silvie discussed how through routine check-ups they would meet and discuss their health which promoted shared understanding and empathy. It is not surprising that participants felt a connection with others who experienced similar illness and transplants given the proximity of these participants who would often share the same transplant hospital and support groups. However, the automatic propinquity developed was also a consequence of shared health and self-management practices.

One participant, Ella, discussed how there are discrepancies between different transplants in terms of self-management practices and health concerns. As a heart transplant recipient, she felt other transplants such as kidneys did not have the same level of attention to care. Ella stated, "you do feel an affinity because you understand the obsession with washing hands, you don't have to sort of explain yourself whereas as the other groups you do sort of have to explain". Here, Ella experienced automatic propinquity with other heart transplant recipients due to the similar health practices they followed. It was the shared understanding of the fragility and seriousness of their health that bonded these heart transplant recipients together. Here, the weaker ties of other recipients promoted their inclusion within Ella's social network due to the shared self-management practices. Jacquie, also a heart transplant recipient, shared similar experiences in that the mutual understanding between other heart transplant recipients is what brings them together, again, promoting their inclusion within her social network. Jacquie explained:

> I think unless you are a transplant recipient it is hard to put into words exactly what you are feeling. But when you talk to another heart recipient you don't have to put it into words because they know what you are feeling.

These perspectives contrast somewhat with one participant's account. For Lauren, her transplant was not the motivation for the friendship but was the initial reason that brought other transplant recipients together. She described:

> The very close friends that I have who are also patients isn't the basis for the relationship it just happens to be the reason why we met. But it's how we came to know each other, it's not the whole reason why we are friends. But I think it is at the beginning, a foot in the door almost. Yeah, and for others who have similar medical circumstances, I can't stand because they wind me up and we just clash so… But I think it's also that judgement between recipients. Like 'oh you drink alcohol' 'should you

> really be doing that' and stuff, and I am like for goodness sake people are adults, can they really choose for themselves.

For Lauren, shared illness, and transplantation experiences, although created a "foot in the door" for a relationship and connection to develop, was not the sole reason for friendships to develop from automatic propinquity. For her, it was important to have other things in common. She articulated this well when discussing how she developed a friendship with another kidney transplant recipient. She said, "She [kidney transplant recipient] and I got really close quickly simply because we are quite similar personality wise. Also, we have the same immune disease called FSGS". Here, it was the combination of shared immune disease with similar personalities that developed this friendship beyond a weak tie acquaintance.

Although this perspective contrasts somewhat with other participants, it is possible to draw connections between them in that the reason for the connection in any instance was due to illness and transplantation. Participants developed friendships through automatic propinquity which became part of their illness self-management networks which evolved through negotiating transliminality and their self-management practices. These friendships were developed as way to look towards a future longevity in health.

Participants also experienced automatic propinquity through the shared experience of participating in Transplant Games events itself. In this case, it was through an interest in sport and being active that brought participants and other transplant recipients together. It was the multi-layered identities as a transplant recipient and athlete that participants could relate to, creating a deeper and more meaningful connection. An important finding here, in line with the aims of this thesis, is that these multi-layered connections were developed and reinforced through competing and meeting others at the Transplant Games. For example, Courtney discussed the automatic propinquity she felt with her Transplant Games badminton partner. She said:

> With my badminton partner we share more emotional stuff. Like she's been going through lots recently, so I think for me as her badminton partner but also as her friend and as a person who has had a transplant, I understand what she is going through and those things. I know what it means, and I know what treatment she might require.

Here, Courtney connects with her badminton partner on an emotional level and explains how the multi-layered relationship they share through being a transplant recipient, a friend and a badminton partner provides a deeper connection and closeness which was reflected in her social

network. Similarly, Jeffry recalls “you have had that near-death experience but then we also have the other common denominator in that we love being involved in sport, and so yeah, we attach on to each other”. Participants shared a transplant identity but also a sporting identity which together promoted the strength of their relationship.

There exists a shared understanding between participants that are all working towards the same goal of maintaining their health and managing their transplant, whilst also demonstrating their new capabilities and raising awareness of transplantation through competing at the Games. In some instances, this shared understanding was enough for participants to feel a connection. Furthermore, the Transplant Games offered a way of bringing similar others together who embodied related health experiences. For another participant, the World Transplant Games were also positively perceived in this way. Jacquie recalled:

> With the World Games, they are a lovely crowd, and you are just accepted. This is what I found with the transplant community; is everybody is accepting of everybody. Everybody just chats. When you are in a recipient group, you are all normal because you are all recipients.

In conjunction to notions of automatic propinquity developed through competing at the Transplant Games, there existed an element of social comparison between competitors. Transplant Games events offered participants the opportunity to compare their health and physical capabilities with others. In some cases, social comparison provided hope and inspiration when participants compared themselves with others. Numerous examples of participants feeling a sense of inspiration were identified in the interviews. Anika reflected on meeting others at Transplant Games events as, “Inspirational, when I met people who had transplants for 40, 50 years it’s just like wow. It helps you think it does happen, it [transplant] can last”. Participants often recalled comparisons between other competitors that emphasised the longevity of the transplant. Joseph describes this in the same way:

> I met a woman from South Florida who had a liver transplant 20 years ago. When I was bowling, there was a man from Maryland who had a kidney transplant like 34 years ago. I just couldn’t believe it. Here they are still living and healthy and doing good.

For Joseph, it was drawing on comparisons between other competitors that he had met at Transplant Games events. Joseph used this as a way of situating his own health expectations against similar others that he had bonded with. However, for some participants it was a combination of witnessing other recipients achieve in sport competition despite severe health conditions. For Jeffry he drew inspiration from these recipients. He recalled, “there is one guy

in his 40s that had a very rough heart condition, and he has had a heart transplant and a lot of complications and stuff, but the guy is just an exceptionally good athlete. He is a triathlete". Moreover, Jeffry reflected on competing in sport with similar others. He said, "so all my competitors were old guys that once were nearly dead. We had updated our wills. We've all been close to death at one point or another". Thus, the analysis suggests that participants drew comparisons between each other to approximate their own health and provide them with a future focused on the longevity of the transplant. It was through situating themselves within a network of similar others that they could better understand their own bodily limits and expectations.

However, social comparison was sought in some scenarios so that participants could position their health against others. In this sense, participants often wanted to compete with recipients with the same transplant or similar illness trajectories. For Julia, this was captured in the way she spoke about competing with other women at the Games:

> There are so few women, so we all race together. All age groups race together so we bike together, and we bike against each other so that was really nice. It was great for all of us, you create this camaraderie cause of the excitement with them, that automatic bond with them. It would be nice if I had someone who was a liver recipient I could bike with, secretly that would be my wish.

Here, it is about a need for competition in the Transplant Games but ideally for that competition to be against those with similar transplants or illness trajectories and characteristics.

Overall, participants found a deeper level of connection with similar others which was multi-layered and situated across their new identities as a transplant recipient and transplant athlete. For many, it was peripheral friendships that had formed because of these shared experiences and identities.

6.4 Negotiating transliminality through sport

Taking part in Transplant Games events impacted on the illness self-management networks of participants through a re-examination of the extent to which participants felt in-between being healthy and ill. This third theme unpacks how participants negotiated their transliminal self

through the proactive action of taking part in sport. Participants reflected on being ill and close to death which they were constantly aware of as they navigated post-transplant life. These existential concerns became a way for participants to frame their behaviours. As Jeffry, a liver and kidney transplant recipient reflected, "I was one good infection away from, you know, curtains". Participants situated their previous selves as being close to death which reflected the seriousness of their illness. For Robert (liver transplant recipient) this meant preparing for his own death:

> I had prepared for my own funeral. I left instructions for my own funeral. And it would not be long after I wrote those instructions. Now doing that, is a fairly life changing thing. Then waking up in intensive care, there are not many that wake up in intensive care and think 'oh that is a good result'.

Both Jeffry and Robert acknowledged the proximity of death throughout their illness journey which they had since moved away from. Reflecting on coming close to death in the past provided a future focus as participants were now looking to navigate the 'extra time' that they had been afforded through transplantation. However, participants were aware of the ongoing management involved in being a transplant recipient as they reflected on the possibility of future infection and disease. Although most participants had come close to death in the past, they knew there was a possibility of returning there again. In this way, participants positioned themselves somewhere between life and death acknowledging their liminal position between being healthy and being ill.

As some participants recognised the unpredictability of their circumstances as a transplant recipient, they acknowledged changes to their health could happen at any moment. Lauren, a kidney recipient, recalled a scenario where her mother asked whether she considered herself as still ill. Lauren recalled, "there are two answers to that, either no not at all, or yes, every day because... yes, I will always have chronic kidney disease it will never go away. Transplantation is a treatment that has got a finite length of time". Here, Lauren refers to the temporality associated with her transplant in that it is bound by a "finite" amount of time before it would lose its functionality and she would return to illness, requiring either dialysis or another transplant in the future. Lauren went on to explain:

> I do not know how long I will have this kidney. I know the average is 10-12 years, but it could fail next month. Or I could have it for 20 years. So, there is absolutely no way of telling but at the same time, I do feel like I am a healthy transplant recipient.

For Lauren, she described herself as a "healthy transplant recipient" acknowledging the paradoxical experiences she faced as a kidney recipient, whilst recognising that this could change over time. Similarly, Toby (also a kidney transplant recipient) shared a comparable experience in that he felt a level of uncertainty with the longevity of his transplant, "there is a constant reality, that reminder that this could pack in at any time". For Toby, he simply refused to acknowledge the proximity of death as he stated, "I have no intention of leaving this planet yet, you know. I want to live to my 80s". Yet, participants remained cautious of their health and were aware that they could return to their previous ill self if their transplants were to fail. Courtney explained:

> Sometimes people would say 'oh the transplant stopped working after 6 months' so obviously you have these doubts in your mind. Cause then you would be back to square one, you know. Like back to dialysis, back to constant cleaning and being sick every time you eat something, you know. These things you kind of think about.

It is clear from this statement that Courtney was addressing the temporal aspects of her health suggesting that transplantation had progressed and improved her health beyond "square one". Participants discussed how life revolved around the transplant which was time bound and limited. The time limitations attached to the transplant evoked fears of the longevity of their health and the hope that another transplant would be forthcoming if they required one. This acted as a constant reminder for participants to manage their health. Further, participants viewed the transplant as a treatment option which enabled them to function without dialysis. As Claire stated, "you know you are not cured. Transplantation is a treatment". In this way, participants developed a mechanistic view of their transplant in that it would fulfil a function until it failed, at which point a new transplant would be required. Thus, the transplant represented an object that improved participants quality of life, something that would require management such as maintaining a healthy lifestyle to prolong the life and function of the transplanted organ to keep participants away from illness.

Taking part in sport acted as a way for transplant recipients to negotiate the fluid, liminal space between being ill and becoming healthy again. Competing in the Transplant Games increased awareness of mortality which promoted concerns about the body and self and these concerns were attributed to the frailty of the return to sickness. All of the participants in this study, to varying degrees, were required to navigate the liminal space within which their health was positioned by enacting healthy behaviours such as maintaining activity, adhering to immunosuppressive treatment, and continuing proactive action through participating in sport.

As participants reflected on their previous concerns with dying, they demonstrated a level of control they had gained in maintaining their health and distancing themselves from illness and death. Robert explained:

> I knew I was dying but I was like hey that's a bit quick... Because I know my own life expectancy, and my life expectancy for a liver patient means I will die around 60. But I also know I can skew the distribution of that in my favour. I can lessen the effects of both heart disease and osteoporosis and reduce the possibility of cancer by being as fit as I can be.

Participating in sport offered participants the opportunity to enact healthy behaviours that would increase the longevity of their transplanted organs. Participants also used sport as a proactive way of dealing with the fears associated with prior ill health or death. Here, participants negotiated their transliminal self through sporting activity.

Most participants used sport to benchmark their health status. For Michael this was an opportunity to prove his post-transplant fitness as he stated, "I realised how fit I was it was unbelievable; I was playing football twice a week, I was playing four or five rounds of golf a week". Michael acknowledged how sport offered a way to check in with how healthy or ill he was as he negotiated the transliminal self. Further, Michael positioned his post-transplant fitness achievements within the fluctuation of his health. Despite his increased levels of sport, he accepted a fluctuating health. He said, "I am just getting over a chest infection but to be fair it's the first one I've had for 8 months".

Sport offered a way of raising participants' awareness of how healthy or ill they were by accentuating their physical capabilities. It is controlling the constant positioning between being healthy and being ill which had become normalised and realised through sport. This transliminal space was a unique position that transplant recipients had to comprehend. Through participating in Transplant Games events, participants could accept the illness and fragility of being a transplant recipient by proving their fitness and physical capabilities.

Participants accepted moving through the transliminal space and the fragility of the transplant as an everyday occurrence. For Joseph he described this as: "you learn to live in your new normal." For some participants, participating in sport provided an opportunity to further normalise the transplant experience. For example, Toby discussed how this new normal became manageable through taking part in Transplant Games events. He stated, "it has really normalised it for me being able to do the sport [Transplant Games events] and have these experiences. Yeah, you know, people are like 'ooh you had a transplant' and you are like

'yeah'. I can't say it doesn't feel special cause it does, but it's normalised it". Toby went on to explain how transplant recipients normalised their health and illness experiences when they discussed their health with each other. Further, it was through participating in the Transplant Games that their health concerns did not dominate the reason for interaction. Toby described:

> You meet with a transplant athlete and there is that team camaraderie of asking 'how you are doing, you good?' And you say 'yeah' and that is it, you move on and talk about other things. When you are playing, it is like you are representing GB and you look around and see all these athletes, but the transplant is not the first thing to come to your mind.

Through participation in Transplant Games events, participants' conversations with other recipients normalised the transplant experience as they moved towards embodying their new transplanted selves focused on being an athlete. Anika articulated this well as she described what the Transplant Games meant to her:

> Yeah, definitely it moves away from it being an illness category that some people would brand it under. It gives you something else to focus on, but for the better. Because you are doing it to improve your body, and I know when you do exercise it does help with your transplant, with your function, and the rest of it as well. It is not just doing it for the sake of it, you are doing it for yourself and you know it benefits the kidney as well.

There was a sense that when participants talked about their illness experiences it was distant from other people's perceptions of their health. Often participants reflected on how others assumed that they were never going to be healthy again. Julia stated, "I sometimes think that people see me like I am going to be sick for the rest of my life!" The lack of understanding from others regarding how transplant recipients negotiated transliminality made it difficult for participants to connect these differing perceptions with their own, given the intimate relationship they had with their own body.

Participants also discussed how they did not want to be defined by their illness and transplant despite the impact it has on their lives. Transliminality was wrapped up within the identities of the participants that were being navigated at the same time. Julia articulated this well as she stated:

> I do not want the transplant to define me. Like, I am well aware that it does and that I am 20% compromised. It does compromise my health a bit, but I am aware of that. I don't want to be part of that, and I never want to use that as an excuse. Otherwise, I would be a sick person and I would not want to see myself as a sick person. I have always believed that you are as sick as you choose to be.

Julia positions her identity away from being a "sick person" and believes that individuals have a choice in how they position their identity through transliminality. Here, sport is of central importance to enacting this choice of negotiating transliminality towards a 'healthy identity'. Similarly, Jeffry discussed how he moved away from this identity of being ill. He said:

> I certainly do not identify as being ill anymore and that is the real joy of all this. I do not have to be an invalid anymore and the Transplant Games and the preparing of the Games and training for the Games puts an exclamation point on that! If you are training for something especially at my age, you have always got some sort of ache or pain but it's in a good way you know. It is nice to have a regular everyday ache and pain, not something that's trying to kill you. And so, part of being healthy is the occasional ache and pain and strain that comes with the territory, and it is a good thing. There is an old song that was like 'I would rather feel bad then nothing at all'.

As participants regained control of their physical capabilities, feeling regular aches and pains was perceived positively as recipients used sport as a way of positioning a stable healthy sense of self. Here, the aches and pains associated with participating in Transplant Games events were separated from their transplant. Further, participants' experience of the Transplant Games helped shape their sporting identities. For some participants they identified strongly as a transplant athlete reinforced through competition at the Games events. For Ella she stated how she was "proud" to be a transplant athlete and participating in Transplant Games events gave her a "sense of achievement". As she described: "I see myself as a transplant athlete and I have a new heart and that is part of me now". Similarly, Michael talked positively about his sport activity levels and how he identified strongly with this new identity which he described as something that "gets me fit and keeps me fit". He said, "absolutely I identify as a transplant athlete. I do something like 40 miles a week walking. Monday, I played 9 holes of golf in the morning and in the evening, I did an hour of 6-a-side football". Another participant, Julia, also resonated with being a transplant athlete. For her, it was the associated health benefits with maintaining an active lifestyle that she identified with. She stated:

> That is what excites me about going to the Transplant Games because to be a transplant athlete you need some vibrancy in your life. And you see it in people's skins too and in their face and how they present in pictures. People look amazing with beautiful skin colours they are not grey looking dead; they look beautifully toned. That is why I am so excited to be around that atmosphere at the World Transplant Games.

The participants identified as a transplant athlete which allowed them to position their self towards being healthy. This moved participants away from illness and instead towards "vibrancy" and an active life.

In contrast, for one participant, the Transplant Games served as a reminder of the severe illness and chronic conditions transplant recipients were negotiating. Courtney stated:

> I could see especially people who had heart or lung transplants, you could see the impact on them- it was obvious for those. You could see that they become much older than their age really was, so that was interesting. I also could see that my mixed doubles badminton partner, I could see he was physically unwell, but I did not know that his kidney function was declining quite so rapidly so I was a bit worried about him.

Although the Transplant Games celebrated life, allowing participants to position themselves towards being well- assuming healthy embodied identities, it also demonstrated the fragility of life that was being negotiated at different stages amongst competitors. Often most participants reflected this at some stage throughout the interviews, discussing the loss of life or return to illness of teammates and other competitors. In this way, sport and taking part in Transplant Games events acted as a vehicle for navigating transliminality.

6.5 Gratitude, survivors' guilt, and obligation to pay it forward

Taking part in Transplant Games events reinforced participants' gratitude towards their donor which was demonstrated in their illness self-management networks. Here, participants' networks reflected self-management practices to prove their worthiness of receiving a transplant which was often represented in the inclusion of other recipients such as those taking part in Transplant Games events. Furthermore, the need to pay it forward and the obligations transplant recipients felt to give something back often promoted continued participation in Transplant Games events, promoting the inclusion of new network members. In turn, this accentuated and confirmed participants' gratuitous behaviour when competing with others who felt the same way.

Participants acknowledged their gratitude for being kept "alive" which signified a level of indebtedness and importance attached to life. It also suggested that participants had moved away from illness and near-death experiences. For Brian, this importance was exemplified in how he spoke about a second chance at life. He said, "I think you realise how lucky you are… I think it is partially physical, but it is a weird mental thing to think about sometimes". For Brian, it was making sense of and being grateful for life that occupied the way he viewed transplantation. Although for Brian, he had received a live kidney donation from his mother

which he felt did not have the same visceral feeling that recipients receiving a deceased organ experienced. He stated:

> People that have had a transplant from a deceased donor there is a huge emotional kind of attachment there. I don't want to feel blasé of live donation, but I feel it's almost like - having received an organ from my mum - it's almost like just getting on with my life and her grandchildren's lives with me as their dad and stuff like that. And just doing normal stuff is almost validation and is kind of what it is all about really.

It was "getting on with life" and "doing normal stuff" that provided Brian with the validation that his transplant was worthwhile. Further, the analysis highlighted discrepancies between live and deceased organ donation, as seen in Brian's account, which impacted on how participants viewed the significance of transplantation. Some participants felt a sense of survivor's guilt attached to receiving an organ from a deceased donor. Toby said, "why is someone else dead and I am not. Why me, why, why, why… It was just my turn and I got a match. Whether there is a god, or it is random, that is just how you have to go with it. We are all insecure about it." For participants who had received an organ from a deceased donor, this was difficult for them to comprehend which manifested as survivor's guilt. Lauren expressed similar feelings as she discussed the complexities when thinking about a deceased donor. She stated:

> I think also maybe a bit of survivor guilt like I am alive, and this other person isn't. Particularly if they know the donor was young or had children or died in some way where they should be alive. Feeling like 'why am I here, and they are not?'.

Participants attempted to make sense of life and death choices that were not within their control as they comprehended why someone had died for their chance to live. For one participant, this was attached to the type of organ that they had received. For Ella, a heart recipient, she felt that there was a bigger significance attached to receiving a heart than other organs. She said:

> For me I think especially when you get a donation of a heart. Because it means the person is dead you know what I mean…That is, so for that family to have made such a courageous decision at a time, must have just been so awful for them. You kind of feel you got to try and do your best. I also think there is a bit about being, not a good person that sounds terrible but being actively involved in the community you know taking part in things.

An expression of gratitude and perceived closeness towards the donor left participants sympathising with what the donor families had to go through. Further, how participants felt towards their donor and the significance of receiving the ultimate 'gift of life' often promoted

behaviours that enacted a sense of duty. This was consistent across the rhetoric of all participants as Toby stated, “I always want to do my donor proud like whatever you do on that day it’s your best. So that is how we have to look at it” For Paulo, this transpired in feeling as though he has a “mission” to fulfil as a result of being kept alive. He notes, “I think it is a mission from me to help other people. It’s hard to describe it but you can be alive, and I must do that”. Interestingly, for Julia, her understanding of living with a new organ whilst acknowledging loss of life manifested in her motivation to maintain a memorial garden for her donor:

> I have these 10 roses, they are a full-time job to look after, I grew them on my old liver, so that is a full-time job, like a memorial, and it just has allowed me to continue, like I haven’t ditched it because I am still alive, so it allowed me to look after it. So, it’s a memorial for the person that gave me this [liver]. Like you look at it like good people go to heaven, so this donor has a little star up there and probably shines on the roses at night-time.

The significance of this moment for the participant suggests that the dutiful behaviour in memory for the donor became part of everyday life. It also was a way of making sense of the complicated nature of organ donation and loss of life.

It was through these dutiful behaviours that participants felt obligated to do their donor proud and pay it forward. Participants often felt obligated to give something back in any way they could. Robert stated, “spend your life planting oak trees you will never see grow”. Similarly, Brian stated, “It’s that whole kind of got to give something back…”. Here both Robert and Brian demonstrated a sense of indebtedness, something that they needed to fulfil in some way.

Participants’ motivation to ‘give something back’ identified in the interviews emerged in a multitude of ways. For Daniel, he felt obligated to promote organ transplantation which was attached to a few reasons. He said,

> The first reason is because, well it saved my life didn’t it? So, I feel, given that I benefitted from it, it sorts of stamps the reason why others should benefit from it too. And I suppose the other reason why I feel obligated is because you can promote it can’t you? You can do research and you can talk about it and all that stuff. I will occasionally sort of pipe up and I would say if organ transplant did not exist, I would be dead now. And my youngest child is four and that would be a horrible tragedy. I think it’s my obligation to at least do that, to say to people look, this thing is miraculous. It’s so important to so many people.

Similarly, Courtney felt that giving something back was also important. She said, “I do a lot for kidney foundation because I am now raising money and I have donations over £5000

already…it was my way of saying thank you". Courtney attached a financial significance to the gratitude she felt for organ donation. However, Courtney also felt that not only was giving back important but also 'paying it forward'. She stated:

> It is not just about giving it back but also paying it forward. You know paying it forward by spreading the awareness in any way you can, so some are using media as part of using media as spreading awareness. Some people are umm entering competitions. Some mentioned they are transplanted themselves.

In this sense, giving back was attached to debt participants felt they owed for a second chance of life. Paying it forward was a way of moving beyond indebtedness. Participants identified multiple ways of giving back and paying it forward as part of their felt obligation as a transplant recipient. It often transpired that participants felt as though they had to raise awareness or give something back as part of being a 'good recipient'. There was a sense that being a good recipient was not just about being compliant with immunosuppressive treatment, but also in giving back.

What became apparent within participants' experiences of the duty, obligation, and guilt they felt was how this was socially determined through their illness self-management networks. It was also through seeing other transplant recipients giving back that promoted a sense of duty to do the same. In this way, giving back and paying it forward was a responsibility spread through illness self-management networks which influenced participants' dutiful behaviours. As Anika recalled:

> I think if you are in a community, you feel like you have to [give back] even though it might not have been said, you know you see other people doing it and you are like wow I feel like I should be doing something. For me it is always about if I can help someone else who doesn't have to wait as long as I did. If I can bring that for people as a support thing then I feel good about it in a sense that I am helping someone. They are not alone like I was.

The significance of this moment for the participant suggests that feeling good was attached to giving back and paying it forward which would suggest this was a way of acknowledging and dealing with the associated guilt of being a transplant recipient which was spread through illness self-management networks.

In conjunction with notions of participating in sport as part of self-care and moving towards being healthy, the analysis also illustrated that this was embedded in the obligation to maintain their health and look after their organs. Here, sport offered an opportunity to fulfil the obligations participants felt towards their health. Silvie stated:

> I think the obligation I guess that I feel is to stay healthy, so yeah, it's like for me it's about being healthy cause I have been given the opportunity and I don't want to show that I have been irresponsible.

Participating in Transplant Games events also offered the opportunity to raise awareness and pay it forward. Further, it offered a way for transplant recipients to seek donor approval through maintaining an active and healthy lifestyle. Brain detailed this when describing how he felt in not attending future Transplant Games events. He stated:

> If I am not going to do the Transplant Games I feel as though I should do something to A. be active and B. promote transplantation. I feel a slight sense of guilt for not going [to the Games]. I have said that to other people, it is almost like you feel like you have a duty to do something. I think that is why I was suggesting that I should do something that raises awareness. Again, if it is not doing the Transplant Games then doing something that raises the profile of Transplant Sport and the benefits of transplantation in that sense.

For Brian, he felt guilty for not continuing his attendance in future Transplant Games events to promote organ donation awareness. In this way, participating in Transplant Games events had a dutiful component that participants resonated with as a way of paying thanks to their donor, raising awareness, and maintaining health- taking ownership of their self-management. Further, it was a way in which participants could deal with the obligation they felt as transplant recipients to pay it forward. Further, participants' illness self-management networks containing weaker ties established through participating in Transplant Games events often confirmed and reinforced these beliefs which promoted continued dutiful behaviour and, in some cases, continued participation in Transplant Games events. However, participants' illness self-management networks also promoted a sense of guilt if participants felt they had not enacted dutiful behaviours or raised awareness sufficiently.

Some participants also externalised their transplanted organ and recognised the assumed identity of the organ donor as the motivating factor for maintenance of health through taking part in Transplant Games events. The following example from one of Jacquie's interviews was particularly revealing. She said:

> I am doing all this because I want to and because I want to keep myself healthy. But also because it is somebody else's heart and not my own. It is because someone has been willing to give up their life for me, that I feel that I have got to stay as fit as I can in their honour. Especially as he [donor] was only 23 years old. You know it was a young heart that I got, so I feel, well I think we all feel that way because we have been given this second chance. A lot of us want to make the most of it. But I think if I had had my own heart, I do not think I would be doing as much as I am doing now. So, I have a reason to do it [Transplant Games events]. But it won't be running it will be

> trotting. I want to honour his memory and I want to make it worthwhile. I don't want him [donor] to think I got it and just sat back and let life go by.

Jacquie acknowledged the separation between her own body and the transplanted organ. She identified how the organ she had received from a male donor was a "young heart" which had once belonged to somebody else. She felt as though this deserved honouring in a sense of maintaining the longevity of the organ. Further, there was a detachment from her own body that motivated Jacquie's health practices including being active. She stated how if she had her "own heart" she would not be as active as she is now.

Overall, participants felt an obligation to give something back and pay it forward through the overwhelming sense of gratitude they felt for their donor. Taking part in Transplant Games events offered a way of honouring the person who had been willing to donate their organs. Further, sport was meaningful in that motivations for not letting life just go by became attached to competing in Transplant Games events. Moreover, participants sought their donor's approval which became imbedded in their self-management practices further confirming their reasons for participating in Transplant Games events. This ultimately impacted their illness self-management networks as participants met others at Transplant Games events. The gratitude that participants expressed became embedded in their illness self-management networks as they met others from Transplant Games events that confirmed these beliefs.

6.6 Summary

Within this chapter I have presented the thematic analysis from all 16 transplant recipients which consisted of four themes including *close tie anxiety*, *automatic propinquity, negotiating transliminality through sport, and gratitude, survivors' guilt*, *and obligation to pay it forward*. Each theme was discussed in turn to establish how taking part in Transplant Games events had an impact on participants' illness self-management networks. Each theme was supported with evidence from all 48 interview transcripts across the 12-month study duration. Within the next chapter I present the longitudinal changes in the thematic analysis.

CHAPTER 7: LONGITUDINAL CHANGES IN THE EXPERIENTIAL ASPECTS OF ILLNESS SELF-MANAGEMENT NETWORKS

7.1 Introduction

Within this chapter I present the longitudinal component of the thematic analysis using sequential matrices and participant case studies. I will address the fourth and final research question; *How do these factors change over the 12-months following participation in Transplant Games events?* The purpose of this chapter is to illustrate changes within the thematic analysis themes over time. The trajectory analysis consisted of the construction of sequential matrices for each participant using the coded extracts from the thematic analysis across all three phases of interviews. After these matrices were created, a second matrix was produced which refined the extracted interview data into executive summaries (Grossoehme & Lipstein, 2016). The thematic analysis which produced four themes (see Chapter 4 for full outline and description of themes) represented all participants' experiences, and subsequently took a cross-sectional viewpoint that did not analyse between the three interview timepoints across the 12-month study duration. Therefore, the sequential matrices offered a way to identify interesting stand out participant cases across each of the four themes over time. The individual cases that were selected, best represented each theme and offered either a unique or extreme viewpoint which provides a rationale and further context for the inclusion of each case study (Baxter & Jack, 2008).

A case study approach offers a novel way of conveying lived experiences in concrete ways to illustrate the findings in depth and further answer the 'how' and 'why' questions of the data (Baxter & Jack, 2008; Yin, 2009, 2018). Table 7.1 provides a sample of a sequential matrix which includes the participants' interview summaries. The four participant case studies were chosen as exemplars that highlighted key components of the themes. Whilst multiple and various participant cases could have demonstrated and represented similar changes across the themes over time it was thought that one case study per theme would provide sufficient depth. The first case study details how Lauren dealt with the *close tie anxiety* over the 12-month study duration. Specifically, this case study will outline how the anxiety experienced by her parents became less significant as Lauren managed these relationships over time as she moved towards stable health. The second case study will outline Joseph's account of *automatic propinquity* in the closeness he experienced with other recipients which developed into friendships over time. The third case study will detail how Daniel *negotiated transliminality through sport* as he fluctuated between illness and being healthy. Here, Daniel's experiences of his health change significantly from the first interview to the final interview which impacts on his interaction with sport. The fourth and final case study unpacks the *gratitude survivor's guilt and obligation*

to pay it forward experienced by Claire as she embedded donor-directed gratitude within her motivations to take part in Transplant Games events. Over time, these motivations became more apparent and allowed for continued participation in Transplant Games events.

For clarity and to facilitate depth of analysis, each respective participant case study will be presented in turn supported with participants' interview extracts across all three interview phases over the 12-month study duration. This will be followed by a summary of each theme to outline the applicability of the longitudinal changes to all other participants in this study. The case studies will include the data coded from the thematic analysis which will include data that has not yet been presented within previous results chapters.

Table 7.1 Extract of matrix displaying summary of changes over the 12-month study duration across each theme represented by each participant case examples.

Case study	Theme	Phase 1	Phase 2	Phase 3
Lauren	**Close tie anxiety**	Parents experienced anxiety which fuelled own anxiety. Formed an emotional boundary between parents as protective factor which was reflected in the placement of parents on periphery of social network.	Boundary between parents still presented as a way of managing anxiety through censoring information shared with them. Regular contact with weaker ties such as recipients, and friends promoted through automatic propinquity.	Parents still situated on the periphery of social network due to their location and consequence of managing close tie anxiety. Health stabilised now, which reduced parents' anxiety although worry still present, but time and distance continued to influence this.
Joseph	**Automatic propinquity**	Automatic bonds initially developed through participation in support group and Transplant Games events impacted network.	Making space in social network for new contacts and automatic propinquity promotes the development of friendships.	The friendships developed through automatic propinquity demonstrated in experiences of a new social circle with members of support group and Transplant Games events.
Daniel	**Negotiating transliminality through sport**	Reflecting on coming close to dying prior to transplantation. Identity starting to position towards being a transplant athlete.	Preparing for future health decline by enacting sport and health behaviours. Identity positioned strongly as a transplant athlete.	Decline in health and physical functioning after competing in Transplant Games events and moved towards illness. Still strong transplant athlete identity and becoming an 'elite warrior'.
Claire	**Gratitude survivors' guilt and obligation to pay it forward**	Expressed gratitude for second chance of life which promoted paying it forward and initial participation in Transplant Games events.	Developed multiple reasons for the need to pay it forward which had now become embedded in participating in Transplant Games events.	Gratitude for donor to prove the positive outcomes of organ donation still main motivation for continued participation in Transplant Games events.

7.2 Case study 1- Lauren: 'There needs to be a boundary between mum and I'

Lauren received a kidney transplant in October 2016 having been on the active waiting list since 2014. During the first interview, Lauren discussed her relationship with her Mum and Dad and how they had experienced mental scars due to her illness which produced anxiety over her health. As a result, Lauren discussed how she would refrain from discussing her health with her parents. She stated:

> I would censor what I told them, simply because they are on the other side of the world. I didn't want them to be extensively worried about something they couldn't do anything about. Also, both mum and I, suffer from, or have suffered from, quite severe anxiety so we kind of feed off each other.

The significance of this moment for Lauren suggests that her close contacts, her parents and more specifically her mother influenced her anxiety levels when discussing her own health with them. This led Lauren to consider how close these members were bound to her and her transplant journey. Further, Lauren discussed how the close tie anxiety, especially from her mother had become an issue which she had sought psychological support and help for. Lauren articulated:

> With the help of a therapist, I have kind of figured out there needs to be a boundary between Mum and I. So, I thought this is kind of my sort of protective factor is not exposing myself to that as it kind of fuels it.

In creating a boundary between herself and her mother as a "protective factor", Lauren had made a conscious decision in managing her health and wellbeing. Further, in doing so, this would reduce her anxiety which was fuelled by conversations with her mum. As Lauren created her social network for the first time during the first interview, she positioned her parents away from the centre circle as less emotionally close than her other network members. Lauren provides a rationale for this in stating:

> So that is why they [parents] are a bit further out from what you would expect somebodies' parents to be [in social network]. Mum and Dad, I would censor what I tell them because of their reaction. Also, what can they really do, other than worry and then fuel my worry.

Here, Lauren had consciously created a barrier between herself and her parents to reduce worry and anxiety. This was also reflected in Lauren's network during the first interview where she had physically distanced her parents, placing them on the peripheries of her network.

During the second interview, Lauren acknowledged the journey she had been through with her parents throughout illness and transplantation discussing how time had passed, which influenced their anxiety. Lauren stated:

> It's only been 2 and a half years now since the transplant which isn't a long time, but a lot of water has gone under the bridge in that time and my parents still live in New Zealand. I haven't seen, aside from mum coming over directly afterwards in the first 2 or 3 months. I haven't seen either of my parents since.

The time that has passed since the transplant impacted how Lauren perceived her parents' anxiety. Whilst Lauren does not directly refer to the time since the first interview, she had indirectly acknowledged how the last six months between the first and second interview contributed to the 'water under the bridge' between her and her parents. During the second interview, she discussed how things had changed since having the transplant with less emphasis on the anxiety produced through conversations with her parents as she moves towards a stable health. Lauren also reflected here, on the physical distance she had between her parents who lived in New Zealand. It was the physical boundary between them which also limited the regularity of contact, making it easier to limit conversations regarding her health. However, Lauren also reflected on how this also became a reason why anxiety still existed between them. She stipulated:

> Neither of them has visited in the last 2 and half years. So, I think that has obviously been a factor as well and they have not seen that I am alright and seen me day to day as a healthy person. But they do know that I am well. I would say they are less anxious about my circumstances now then perhaps they would have been six months ago. I mean I do not know whether I am the only one who has their immediate family on the other side of the world so obviously that has been a factor for me as well. So obviously my parents are not in close physical contact with me, they do not see me every day.

As Lauren's parents cannot physically see how well she is doing they can only accept what Lauren filters to them through phone calls as the reality of her ongoing health status. While in some cases the physical boundary helped limit conversations regarding Lauren's health, it also reduced the chance for her parents to see how well she is as her health had now stabilised.

Due to the physical and emotional boundary between Lauren and her parents, she reflected on how she had sought support from typically less emotionally close ties. This became apparent within the second interview which demonstrates how Lauren sought to manage this anxiety over time. Here, Lauren discussed at length how the proximity of weaker ties such as other dialysis patients and transplant recipients meant that they would be called on for support in replace of her emotionally and physically distant parents. She stated:

> My other friends, recipients, or dialysis patients I see them a lot more regularly. They get it because they have been through transplantation or are going through it, or they might be going through it in the future. So, I think that I do speak a lot more freely to my friends then I do to my parents and that is for two reasons really. One- I am still very aware that I must manage my parents' anxiety, which in my case means censoring almost what I tell them. Whereas with my friends I can be more open cause I know that they are not going to panic because they even know yes, it is serious, but you will very likely end up fine.

Lauren had more regular contact with her less close contacts which enabled a more free, open, and rational conversation when discussing her health. Thus, promoting the strength of weaker ties within Lauren's illness self-management network impacted from attending Transplant Games events. The proactive way in which Lauren decided to manage close tie anxiety developed over time between the first and second interview.

From this second interview, part of self-managing for Lauren, became her ability to manage her parent's anxiety regarding her health. That is, since the first interview Lauren had learnt how to deal with and manage her relationship with her parents providing them with sufficient information to reduce their worry and anxiety levels. Lauren stated how she would regularly update them over WhatsApp stating to them; "I have nothing to report- quick check in the clinic today all fine".

Furthermore, through participating in Transplant Games events, Lauren had developed friendships which had become part of how she managed her health. She stated:

> I mean I have only attended the Transplant Games once in Birmingham last year and I am headed to Newport in July as well. For me, all my close friends were kind of there as well so I would say that I shared stories and we had discussions.

Here, Lauren could share her health concerns and have discussions with other recipients and friends to limit these interactions with her parents. From the first interview to the second, it was clear that Lauren had developed ways to manage her parents' anxiety and worry.

During the final interview, Lauren articulates how she had been managing her parents' anxiety and worry as she considered the temporal element more explicitly. Lauren stated:

> I think they are always going to worry about me but maybe less than they used to, maybe it is a time thing. I think obviously since I first spoke to you it has been another year so it's settled down cause my health is stable and obviously my parents would ask me, so all I would do is send a WhatsApp after clinic and say all is fine and that's all I would say. So that does ease their anxiety a bit, but I think they are always going to worry about me but maybe less than they used to, maybe it is a time thing.

Here, Lauren came to terms with how time had passed since her transplant and first interview which had influenced the anxiety experienced by her parents. Although, there existed a level of uncertainty over whether her parents worry would always be present, Lauren was able to manage this through her interactions and filtering information regarding her health. This was a consistent practice in managing their anxiety from the second interview. Furthermore, the positioning of her parents within Lauren's network was still considered as less close than the rest of her network. Part of the management of her parents' anxiety and worry may have been to consciously perceive her parents as less close than the rest of her network, placing them on the periphery of her sociogram which was consistent across interviews.

Overall, close tie anxiety is threaded through all three interviews over the 12-month study duration as Lauren dealt with her ongoing health and self-management. Since the first interview, Lauren's parents' anxiety had reduced which in turn decreased Lauren's anxieties. Lauren attributed the reduction in close tie anxiety due to her ability to manage her parents' anxieties with careful interactions – a pattern that was consistently seen across the second and final interviews. Lauren was able to manage daily interactions with her parents due to the distance between them. Furthermore, the promotion of weaker ties which were called on to discuss her health concerns with, reduced the need to discuss these concerns with her parents. Finally, Lauren also attributed being able to better manage her parents anxiety due to the time that had passed since the start of the study which lessened the worry.

7.2.1 Summary of close tie anxiety

Close tie anxiety varied across participants over time and was significantly influenced by participants' health and the automatic propinquity experienced with others. During the first interview, most participants reported the anxiety of close family including parents, siblings, children, spouse, and partners. Many of the participants often discussed how this constant worry reduced the contact they had with close ties when discussing their health, promoting the strength of weaker ties. Across the second interview, most participants discussed how close tie anxiety was still present as they often spoke about how they had come to manage this through limiting their contact with closer ties when it came to sharing information regarding their health.

Across the final interviews, participants had embedded ways of managing their close tie anxiety within their self-management practices. Here, it became less of a conscious worry

that would induce participants' own anxiety and, instead, participants had integrated the ways of managing this within their daily routines.

In most cases, participants emphasised how the time that had passed since transplantation often reduced anxiety experienced as their health had become stable. Although for some who had moved towards illness again, the anxiety and worry had increased as close relationships became fractured. Here, time since transplant and negotiating transliminality influenced mental scars and close tie anxiety rather than participation in the Transplant Games. Therefore, we cannot assume participation in Transplant Games events could influence the negative emotional responses with close tie interactions. However, the analysis did discover how support from weaker ties could be a useful way of managing the anxiety and worry of close ties. This demonstrates the meaningfulness of weaker ties for self-management outcomes. Moreover, these weaker ties could have been gained through participation in Transplant Games events which may have reduced the work of participants' close ties.

7.3 Case study 2- Joseph: 'We are all in it together, it's like a whole new circle'

Joseph received a liver transplant in 2017 and had been two years post-transplant at the start of the study. During the first interview, Joseph discussed the shared empathy and shared experience of receiving a transplant that created an instant bond with other recipients. This instant bond was reflected in the inclusion of other transplant recipients within Joseph's social network. Joseph stated, "I never knew anyone that had had a transplant and now it's like all the closest people in my network and the support group have all had transplants". Here, Joseph reflects on how his network had changed post-transplant because of automatic propinquity. Joseph stated, "I feel like it's important you know at first I didn't know how long I would be part of this support group; they say seven weeks after surgery and then you go back home to your normal real life". Interestingly, for Joseph, the automatic propinquity developed with members of his support group promoted prolonged involvement.

As Joseph looked after his future health, he gained a sense of hope in the longevity of a life after transplantation through shared stories when meeting similar others when competing at the Transplant Games. He stated:

> I met a woman from South Florida who had a liver transplant 20 years ago when I was bowling. There was also a man from Maryland who had a kidney transplant like 34 years ago, I just could not believe it. Here they are still living and healthy and doing good. So, it gave me a lot of hope. I met a family at the Games that has a 17-year-old boy that is an amazing athlete, and he got a liver at 5 months old. He was born with a bad liver and at five months he had a transplant and he's got a wonderful full life.

Joseph used these stories as a way of comparing and situating his own health in a positive way as he looked towards fulfilling a normal and healthy life. Here, social comparison drew Joseph closer to other recipients as they shared stories and compared their similar illness experiences. In this way, the impact of the stories on Josephs' outlook was due to the relatedness and closeness Joseph initially experienced with these individuals in the first place. However, friendships did not need to develop to share stories. Instead, automatic propinquity offered a way to connect and interact based on shared and lived experiences.

During the second interview, Joseph discussed the influence of experiencing a closeness with other transplant recipients met through both his support group and the Transplant Games. Of interest here was how Joseph had actively 'made space' for these new transplant recipients within his social network. He stated:

> So, I have the opportunity to meet all new people, but I have to make space on my Facebook page for all the new friends I meet. I am a member of several sites. One is for the Transplant Games of America. And locally we have our support group with 250 members and everyone on their wants to know every step of my journey to the Games. So that is just a good way to keep up with it. But I hear from people still regularly who I met in Salt Lake City this past year.

Here, Joseph had embedded himself within the Transplant Games and recipient networks associated with his support group and was actively engaging with these members as a source of support. A similarity between the first interview and the second was that Joseph consistently recalled stories from interactions with other liver transplant recipients for inspiration and hope. Further, it was through continued participation in Transplant Games events that provided a platform for continuing to meet recipients and further develop these bonds:

> I met a young man that just graduated from High school, 18 years old, who got his new liver at 6- months. So, he has had his liver for almost 18 years, and I am hoping that he will come to the Transplant Games next year.

Joseph acknowledges the significance of the automatic bond he shared with another liver transplant who had similar illness experiences further emphasising the length of time since transplant as he gains assurances in his own transplant longevity and illness trajectory. Joseph only recites stories of liver transplant recipients due to the direct connection with his own

circumstances. The automatic propinquity between liver transplant recipients as they compared illness trajectories was evident throughout Joseph's first and second interviews. The difference here was that over time, between interviews, the closeness Joseph experienced with these recipients had developed from passive engagement to active engagement which promoted further development of these bonds which became apparent as Joseph looked towards the future.

During the final interview, Joseph emphasised the central importance of the support group he was a part of which had become embedded within his network. The importance attributed to this support group shows significant change from the first interview where Joseph was unsure of his future commitment to the group. This demonstrates how automatic propinquity offered a way to connect with others. In Joseph's case, this then promoted a closeness with others which developed over time through prolonged active engagement with the group. In this way, automatic propinquity acted as the initial foot in the door whereby meaningful friendships could then develop. Here, Joseph identified the value in the connection he shared with other liver recipients that have had similar health concerns. Joseph stipulated, "I got to be very close with people in my support group that meets every Tuesday for an hour and it's mostly liver transplants". Here, Joseph confirms the importance he had now attributed to the role of this group with his illness self-management. Further, the automatic propinquity experienced with his support group initially had moved from providing emotional and informational support towards developed friendships as Joseph discussed how he had started to meet socially with members. This emphasises the change that occurred between the first interview and the last interview where automatic propinquity promoted prolonged engagement and the development of friendships. Joseph stated:

> You know what is so good about the support group is if I have a problem I can ask because mostly everyone has had the same problem through the years. I do things socially from my support group now because we are all in it together so it's like a whole new circle.

This new circle within Joseph's social network gained through automatic propinquity with other transplant recipients met through his support group and participating in the Transplant Games provided Joseph with hope and a future focus on the longevity of his liver transplant. It was through social comparison, shared stories, and empathy that further connected recipients together. As Joseph looks towards the future, he acknowledged how his network will increase as he competes in future Transplant Games.

Overall, it is clear from the first interview that automatic propinquity was initially experienced through shared experiences and similar illnesses which promoted sustained commitment to the support group. Continued involvement in the support group, which developed into active engagement, promoted the initial connections to friendships over time which became evident by the final interview. Here, it seemed as though automatic propinquity became less important over time as stronger connections were established with individuals which then turned into friendships. In this way, automatic propinquity was important when establishing connections with weaker unknown ties, but once a connection had been established and friendships had started to form, automatic propinquity became less prominent. Furthermore, it was the friendships Joseph had developed which were reflected in his social network over time.

7.3.1 Summary of automatic propinquity

In reviewing automatic propinquity across all participants, I found that automatic propinquity was often influenced by participants' own illness trajectory and life circumstances. During the first interview most participants often reported experiencing a closeness with others who had similar transplants or illness trajectories which positively influenced participants' networks as they experienced bonds through near death experiences and taking part in the Transplant Games. In some cases, this was time sensitive as closer bonds were formed with those that received transplants at similar times.

Across the second phase of interviews, the closeness participants experienced with other recipients often turned into friendships as they shared stories, empathy, and similar experiences, including the uniqueness of transliminality. This demonstrates how automatic propinquity develops over time in that it was initially important for individuals to share similar experiences to form a connection such as receiving the same transplant, but as they managed their health over time, they could share their ongoing post-transplant experiences. Furthermore, continued participation in Transplant Games events allowed for regular contact between these new ties which helps establish the impact of participating in Transplant Games events for the first time and the impact over time. Conversely, we may consider how long these bonds would last without continued participation in Transplant Games events. However, for some participants, they did not feel close to others met through Transplant Games events and did not feel the need to share stories or socialise. For these participants taking part in Transplant Games

events, was due to the associated health benefits and to demonstrate gratitude rather than to form friendships. These individuals formed bonds with others met through other means. Although, most participants had continued their participation in Transplant Games events following their first time, promoting regular contact with weaker ties which then formed into stronger friendships. Across the final interviews, some participants moved beyond automatic closeness because of shared illness experiences and found other reasons to form friendships with other recipients. Here, participants situated these friendships outside of their identities as a transplant recipient or transplant athlete and positioned this more towards their similar life course. In this way, automatic propinquity changes over time, in that, once connections had been established, other reasons for forming friendships became apparent.

7.4 Case study 3- Daniel: 'Becoming a transplant athlete is like becoming an elite warrior'

Daniel received a liver transplant in 2016 having been on the active waiting list since 2015. At the time of the first interview, Daniel was 2 years post-transplant and had just competed in his first Transplant Games event, medalling in the 5k and 1500m events. Daniel provided a background of his health and medical history during the first injury which reflected on his previous ill-self as he emphasised how he was close to death during and throughout his illness prior to his transplant. Daniel stated:

> The thing is, basically I felt like I was dying. My body seemed to be saying, it was quite clear to me really, it was not an intellectual feeling. It was like a feeling in my gut that I was dying and of course I was dying. So, I think it was quite accurate.

Here, Daniel reflected on his illness journey with emphasis on his ill-self. Daniel talked at length about how his body managed the transitionary period which was difficult for him to comprehend. Daniel said:

> I found it really difficult to cope with. I wake up in the morning and that is what my body would tell me. The first thing my body would tell me is to not get out of bed and the second thing he would say is that it was coming to an end. The book was closing, and it was very difficult.

Despite this difficult moment of feeling close to death that Daniel experienced prior to his transplant, he discussed how he used sport as the motivating factor to move towards being healthy post-transplant. In this way, sport was used to navigate his transliminal self. Daniels'

motivation was evident during the first interview which led to his initial involvement in Transplant Games events. Daniel drew on his previous sporting history and identity as a martial arts performer to reinforce his motivation to compete in the Games and resume a sporting identity. Daniel explained:

> So, straight away you know that to me, obviously being someone who was quite competitive and sporty that was something that I immediately latched onto as being [a transplant sport competitor]. Something that would be good, to get better enough to do after my transplant.

Here, Daniel used sport as a way of moving towards an identity positioned away from illness, which was a way of navigating transliminality. Daniel's competitive nature developed through his previous sporting history provided a motivating factor to move towards being healthy post-transplant. Throughout the first interview it was clear that Daniel had started to develop a new sense of self positioned through participation in the Transplant Games. In this instance the Transplant Games acted as a replacement for his previous sporting commitments and identity within martial arts which he had to retire from due to poor health and transplantation.

During Daniel's second interview, six months on from the first, it was clear that transliminality was temporally bound and attached to his sporting commitments and capabilities. Here, Daniel now acknowledged an eventual decline in health and through using sport was able to prepare for this. This was strikingly different from his first interview where Daniel had positioned his health away from illness by taking part in the Transplant Games. During this second interview, Daniel had acknowledged the uncertainty of his health and the potential health declines he expected to face soon, despite acknowledging good health six months prior. Here, Daniel prepared for this decline by keeping fit and healthy as he used sport as a way of preparing for eventual health deterioration. This is where the temporal nature of Daniel's health becomes apparent as he recalled the conversation with his anaesthetist as he prepared for his transplant. Daniel reflected on how he would like this interaction to go in the future as he prepared for future operations. As he explained:

> The anaesthetist was like, 'you are strong, fit and health so you will be fine'. And I want to have that exact same conversation next time. I do not want him to be sucking his teeth and saying well, 'if only you were a bit thinner'. I want him to be saying 'yup we can do this you are fine, done, finished'.

Daniel acknowledged the temporal changes associated with his transliminal self as a transplant recipient as he prepared his body for further operations. Again, Daniel used sport as a way to account for the temporal changes to his transliminal self but also as a benchmark for where he

wants his health to be as he prepares for what he would describe as the 'inevitable'- move towards illness. Furthermore, Daniel also uses participating in the Transplant Games to reconstruct his sporting identity due to the loss of his martial arts status. Throughout the second interview it was clear that his martial arts status was significant in his life, something he could no longer enact. Daniel articulated:

> Martial arts were part of my identity for a long time. I have had to just give it up because it is way too dangerous. So, I have lost that. But I identify as an athlete now, and I have noticed very recently, what I call myself now is a transplant athlete. And that almost feels like a new identity. I feel quite happy with that really.

Here, Daniel strongly identified as a transplant athlete having competed in the Transplant Games for the first time, successfully. This demonstrated change between interviews as Daniel had now developed a strong transplant athlete identity which was not as apparent during the first interview. Daniel's new transplant athlete identity helped him position his health away from illness and towards competing in the next Transplant Games, a year on from the first. Further, Daniel could use this future focus to maintain his health and his sporting identity whilst also using it to benchmark fluctuations over time and prepare for illness. In this sense, the temporal nature of his health as a transplant recipient becomes a focus throughout his sporting competitions.

During the final interview, Daniel reaffirmed his identity as a transplant athlete which had become more apparent throughout the interviews and specifically of central focus within the final interview. He explained:

> I have written transplant athlete on my twitter profile because it made me realise that it was a big part of my life. I think for me, martial arts are not about killing people it is about becoming an elite warrior and pushing yourself. I think there are lots of ways you can do that. And I think being a transplant athlete is one of them because you know, transplant athletes, not only do they have to overcome training, but they also have to keep themselves fit as well. That almost feels like part of the sport to me. It is just staying well and keeping on top of it.

As a transplant athlete, Daniel could position his new identity within his old sporting identity as an 'elite warrior' which determined how he handled transliminality. For Daniel, being a transplant athlete encompassed illness self-management and keeping fit and healthy which had become a full-time job. Daniel stated, "being a transplant athlete is like a 24-hour job. It is about putting the hours in and showing up to work and being ill and going to the doctor and going anyway… it's just about fighting". Here, negotiating transliminality had become embedded in his sporting identity.

At the time of the final interview Daniel had competed in his second Transplant Games event. As Daniel used the Games to benchmark his health, he had come to realise that his health had deteriorated. Daniel explained:

> I was in the Games and I did pretty well, but I did not feel well throughout that entire time. Then I was in hospital again in September and I just haven't been right since. I had been to the gym a couple of times. I was at the stage a month ago where I could just about exercise, but I felt like I was wasting valuable energy.

Daniel had moved towards being ill again, something he had prepared for, which instantly limited his level of future sports activity having to now account for the varying health challenges he faced. Daniel articulated this well when speaking about the impact that running now had on his body. He stated:

> So, you can theoretically exercise but all you are doing is making your life harder. And I reached that point a month ago so, I really need to talk to the doctors on Monday. I don't know what they are going to say, but I have just given it [exercise] all up. It is not worth it. So, I have put my trainers away.

Daniel accepted the limitations due to his recent health decline and at this point had ceased training and sporting involvement to maintain his energy levels for everyday work. This impacted Daniel's network which reflected the reduced physical capabilities and sporting involvement with less actors included within his final sociogram.

Overall, it became apparent how Daniel had repositioned his sporting identity away from martial arts towards being a transplant athlete. Furthermore, Daniel positioned his health through his sporting commitments and achievements, and throughout each interview these components of his life became well integrated. Daniel's fluctuating health impacted on his ability to enact sport and take part in Transplant Games events. Despite this, he still strongly identified as a transplant athlete. Here, Daniel had integrated his illness and ongoing self-management within being a transplant athlete which maintained his sporting identity as an 'elite warrior'. In this way, Daniels' sporting identity became an integral way in which he handled the transliminal self.

7.4.1 Summary of negotiating transliminality through sport

During the first phase of interviews, many of the participants within this study reflected on their ill health prior to transplantation as they moved towards acknowledging a change to their identity between the different subject positions of being a patient, a transplant recipient, and an

athlete. During the second interview, most participants' accounts moved towards increasing physical functioning having participated in Transplant Games events as they moved away from illness. However, for some, illness was still present as they coped with fluctuations in their health. During the final interview, many participants had come to acknowledge the uncertainty of their health through an increased awareness of their bodily changes. Some participants moved towards a stable healthy self, whilst others moved towards illness again. However, competing in Transplant Games events became integrated with how participants dealt with transliminality which was temporally bound and dependent on continued involvement following participants' first-time participation. Continued participation in Transplant Games events often promoted stability in ones' sense of self and greater acceptance over fluctuating health. Overall, most participants' accounts across three interviews over the 12-month study duration reflected the fragility of their health as they managed changes to their own health which evolved at varied rates.

7.5 Case study 4- Claire: 'I need to promote organ donation and to show the world that you do get a second chance with life'.

Claire received a kidney transplant in 2017 and was 2 years post-transplant at the start of the study. During the first interview, Claire reflected on how she had moved from being severely ill to receiving a transplant which had given her a sense of indebtedness post-transplant. Claire said, "You look at things differently because I kind of went so far as to be so very, very ill in intensive care so then everything after that really was a bonus". Claire emphasised how transplantation had given her a different outlook on life. The emphasis on the second chance of life and the gratitude she expressed also promoted her initial participation in the Transplant Games. For Claire, it was giving back to others who were going through similar experiences with chronic illness that occupied this need to give back. During the initial interview, Claire had embarked on a training course in self-management and leadership to fulfil this obligation. Claire stated:

> I have done a self-management course with the Irish Kidney Association called 'better health better living'. And that is for people suffering with all types of chronic illness. After I did that, myself and a few others that are in the Irish Kidney Association went up to Dublin and got a leadership training course on being able to deliver that course to

> other people. So, we are waiting for a group of people now to be formed so that we can give that course to others here where I live.

Here, Claire could give something back through upskilling and training in self-management and leadership to provide support to others who experienced chronic illness.

During the second interview Claire had developed multiple reasons for why she felt the need to give something back which had now become fully embedded in participating in the Transplant Games. Here, Claire discussed how the Games acted as a potential outlet for paying it forward and as an opportunity to fulfil the multiple obligations she felt as a recipient. She said:

> I am a living donor recipient. The first reason I even started thinking about the Games was to promote organ donor awareness. The second reason in line to that would have been to do it in thanks for receiving my donor. And the third thing which is equally important would be for me to include fitness in my life permanently. In order for me to maintain good health, exercise has to be part of that you know. They are my reasons. I need to promote organ donation and to show the world that you do get a second chance with life.

Claire had moved beyond providing self-management support to others dealing with chronic illness, towards demonstrating her own ability to self-manage through taking part in Transplant Games events. Here, Claire could promote organ donation and pay thanks to her donor by competing in Transplant Games events, something not considered during the first interview. Furthermore, Claire referred to herself as a 'living donor recipient', which somewhat subtly distinguishes between the impact of living versus deceased donation for the recipient. However, as a living recipient, Claire still had clear reasoning for taking part in the Games which were grounded in the complexity of receiving the 'gift of life' and the need to pay it forward.

During the final interview Claire discussed how the initial reasons for taking part in the Transplant Games, which were integrated in the obligations she felt as a living transplant recipient, had grounded her motivation to compete further in the Transplant Games. Additionally, Claire still associated this with the gratitude she felt for her donor. However, the donor-directed gratitude became less of a burden over time as Claire emphasised how her motivation was positioned towards promoting the positive outcomes of organ donation. Claire recalled:

> Well for me it is a goal I set that is my motivation. I am not doing it for medals. I could say I am doing it for my donor, but it is my sister-in-law through paired exchange. So, I just want to prove the positive outcomes of organ donation. I think at the end of the

> day that is what the Transplant Games is all about - what can be achieved after the transplant or while on dialysis. I have so much respect for these people cause all I wanted to do is just sit on the couch. So, I am just going there, and I will participate. That is what I want to achieve and if I win a medal that would be great.

Here, Claire used the Transplant Games to not only enact healthy behaviours but to position her obligation towards personal outcomes. Further, the Games promoted engagement in healthy behaviours which Claire attributed to caring for the gift of life. She said:

> I feel having been given this gift you have got to care for it as well as possible. Even in general, I feel if you are training, you have to eat well. So, you are looking at your nutrition and that has a positive effect on everyone in the family and everything.

It was through enacting healthy behaviours which were promoted through participating in Transplant Games events that Claire believed would benefit her health, her transplant, and her family. Furthermore, Claire attached additional reasoning as to why she competes in Transplant Games events which became integrated into her daily life over time.

Overall, Claire's appreciation and gratitude towards her donor was evident throughout. Further, she also acknowledges having a second chance of life which promoted the obligation to give something back. Over time, Claire moved towards paying it forward by providing support to other chronically ill recipients and by taking part in the Transplant Games. For Claire, participating in the Transplant Games offered an opportunity to showcase the success of transplantation and raise awareness for organ donation. It was here where Claire attached her reasons and obligations which became embedded and integrated in her motivations to compete in future Games events. Due to varied and somewhat individual differences between participants it is difficult to distinguish here how Claire's experiences could be applied to others. However, what can be applied here is how gratitude and the need to pay it forward became ingrained in participants' motivations to participate in Transplant Games events.

7.5.1 Summary of gratitude, survivors' guilt, and obligation to pay it forward

Participants took part in Transplant Games events as a way of fulfilling obligations to give back which was often reinforced and embedded within participants' social networks, influencing behaviour. Throughout the trajectory analysis, participants' experiences of gratitude, survivors' guilt, and obligation to pay it forward varied across the 12-month study duration. During the initial interview, some participants experienced gratitude towards the donor whilst others expressed survivors guilt in being kept alive whilst most participants who had received a

deceased organ expressed the significance of organ donation, often consistent throughout all three interviews. In some cases, participants who had received a transplant from a deceased donor also discussed paying it forward by raising awareness, supporting others illness journeys, and giving back through taking part in Transplant Games events. For these participants, this was more explicit within their opening accounts and throughout their first interviews.

Across the second phase of interviews, most participants attached donor-directed gratitude, paying it forward and obligation to give back to their reasons for competing in Transplant Games events. Here, participants used the Transplant Games as a way of reducing the survivor's guilt experienced. During the final interviews, most participants still expressed gratitude towards their donor which motivated their continued involvement in the Games and their self-management practices. This was the most significant change seen across interviews in that since first attending the Transplant Games, participants had attached a deeper meaning to their continued involvement. Finally, some participants, had come to accept the significance of transplantation for them over the course of the three interviews which reduced the survivor's guilt experienced. However, most participants still found it difficult to discuss the significance of their donor and the consequence of receiving the 'gift of life'.

Overall, whilst change is apparent within this theme over 12 months, there is no meaningful increase or decline in the way participants spoke about the gratitude, survivors' guilt, or obligation to pay it forward between interviews over the 12-month study duration. However, participants often attached gratitude, survivors' guilt, and obligation to pay it forward to their reasons for competing in Transplant Games events which was consistently spoken about by participants over time.

7.6 Summary

This chapter highlighted how participants, during the first interview, often retrospectively recalled the history of their illness and transplantation and often reflected on life up to the present moment. It was through further interviews that participants started to acknowledge and come to share their present moment experiences. Further, this chapter has discovered how the temporal nature of participants' experiences were wide reaching often not linear or chronologically determined. Instead, the experiences shared across the three phases of

interviews throughout the 12-month study duration followed a much more unstructured view of the participants' worlds as they coped with individual illness trajectories through competing in the Transplant Games. In the next chapter I will present the discussion which will examine the findings from Chapters 4-7. Here, I will highlight how these findings relate to previous research and how they have addressed the research questions. In considering the contribution of these findings to existing literature, the chapter will also outline the limitations and wider impact of this research.

CHAPTER 8: DISCUSSION

8.1 Introduction

Within this chapter I present the discussion of the thesis in line with the aim and research questions of this study. To reiterate, the aim of this study was to investigate transplant recipients' experiences of participation in Transplant Games events for the first time and to understand the impact this had on their illness self-management networks over time. Furthermore, I examined how shared experiences and meeting similar others influenced how transplant recipients perceived their illness trajectory and self-management experiences, as well as better understand how this evolves over time. This chapter is dedicated to discussing the relevance of the key findings of this study with reference to existing relevant literature. Here, I will discuss how the findings contribute to the literature and address the gaps in knowledge. Further, the implications of the study will be discussed to offer some recommendations for how this new knowledge might be applied. Throughout the chapter, the strengths, and limitations of the study will be noted which will offer points of guidance for future work.

8.2 The influence of network types on illness self-management

It is clear from the analysis that participants had different types of networks that were considered important to their illness self-management. The network types produced useful insights which help in determining what characterises the networks of transplant recipients having participated in the Transplant Games for the first time. The network types across all participants included family-focused, friend-focused, family-friend focused, and diverse-sport focused networks. In most cases, participants overall network types were not initially influenced by participation in Transplant Games events despite the influence Transplant Games actors had on participants' illness self-management. However, for the few participants that had diverse-sport focused networks, they considered Transplant Games members as very close within their network which influenced the overall type of network. Whilst this finding of the types of networks for transplant recipients is considered novel, I will position these findings within the wider health literature.

Literature focused on the health and illness of ageing populations have found a range of network types informed by network characteristics which can influence and impact on

health. The findings within this study have extended previous network research across wider health literature that has determined similar network types across various populations (Litwin, 1995, 2001; Litwin & Shiovitz-Ezra, 2011; Spencer & Pahl, 2006; Vassilev et al., 2016; Wenger, 1991). According to Wenger (1987) network types determine different service needs which may impact on wider health outcomes. The authors found five different and distinct types of networks from a qualitative study which included, family dependent, locally integrated, local self-contained, wider community focused and private restricted. The authors found that the locally integrated and wider community focused networks were larger, associated with higher levels of morale and lower levels of isolation. In support of the early work of Wenger (1987), Litwin (2001) found diverse and friend-focused networks to have the highest morale where family and restricted networks had the lowest levels of morale. This finding in the impact of these two types of networks on morale further confirms earlier work which found that these types of networks offer a more robust ability for individuals to cope (Granovetter, 1977).

Within this study, I found that family-focused and friend-focused networks were the most common network types across participants. This is consistent with Morris, Kennedy, and Sanders (2016) who conducted a similar longitudinal qualitative design to understand relationships over 12-month duration. The authors found three types of networks which included family-focused and friend-focused networks important for the long-term condition management. The work of Morris et al. (2016) contributed to the literature through moving beyond individual level self-management definitions to examine how social networks and social processes influenced self-management. Furthermore, the work of Morris et al. (2016) supports the previous work of Wenger (1987) and Litwin (2001) in supporting the role of friend-focused networks. I extend this finding by offering insight into how similar types of networks are important for transplant recipients' illness self-management.

Despite the known influence types of networks have on the illness self-management of people with long term conditions, the types of networks of transplant recipients has received little empirical investigation. Therefore, this study extends the work of Morris et al. (2016), Litwin (2001) and Wenger (1987) to a new population. Furthermore, this study found that family-focused and friend-focused networks were the most consistent network types over time. Consistent with previous research, this study has found how family network types remain stable over time (Wellman, Wong, Tindall, & Nazer, 1997; Wenger, 1991). Network types may have important implications for individuals self-management which can further establish the links

between how the types of transplant recipients' social networks influence and impact on their self-management over time. It is therefore important to understand how the types identified in this study contribute to previous research that has offered connections with the self-management across ill populations.

Vassilev et al. (2016) identified a gap in the existing literature which had not considered network types with people with long-term conditions and how this may impact on their self-management practices and outcomes. Vassilev et al. (2016) found five types of networks with people with long term conditions which included restricted, minimal-family, family, weak ties, and diverse network types. The authors found that those with restricted networks had the poorest self-management with less support received from their network ties, whereas diverse networks were associated with higher levels of emotional support and enhanced self-management skills. Furthermore, those with diverse networks were found to better manage illness due to the range of network members and connections within their network. This is further supported by previous research that has drawn associations between social involvement and the management of long-term conditions (Reeves et al., 2014; Vassilev et al., 2014). However, within this thesis, not all participants gained diverse-sport focused networks from their social involvement of participating in Transplant Games events for the first time. This may be explained in terms of the emotional closeness participants attributed to their Transplant Games actors or it may be due to the infancy of these ties which have yet to become established within the network. Participants who perceived their Transplant Games actors as very close alongside their existing network, central to their illness self-management, had diverse-sport focused networks. Participants who perceived these network members as less close represented other the network types. Vassilev et al. (2016) found that diverse networks were likely to offer greater capacity for changes and when handling ongoing management of long-term conditions. Further, these diverse networks act as a buffer for relationships where change may be more problematic such as with close family ties.

Li and Zhang (2015) also found support for how diverse network types were more beneficial to health outcomes for older adults. However, the authors found that those with decreasing health tended to withdraw from more beneficial network types such as diverse networks shifting towards family-focused networks or restricted networks. This may explain how the network types changed over time and may also illuminate the dynamic nature of participants' networks impacted by their fluctuating health. That is, participants positioned their network type in proximity to their health. Put simply, participants' social networks and

their health status reciprocally influenced each other. This has been supported by the work of Morris et al. (2016) who found that changes within individuals' networks were mutually influential with their health. Morris et al. (2016) found that participants sought types of support dependent on how they managed their ongoing health and illness. Those who experienced a decline in their health positioned their network towards illness work with other work perceived less important. Within this current study, I found that participants positioned their network towards health practices that embodied their self-management. This included other transplant recipients or Transplant Games competitors met through taking part in Transplant Games events. The network members that demonstrated unhealthy behaviours or those that did not align with participants self-management practices were perceived as less close which in some cases influenced the overall types of participants' networks. Therefore, the types of networks and how they changed may be better explained in terms of health status and the impact of fluctuating health.

As health status is bound in the identities of participants, the dynamic nature of the network characteristics also demonstrated the way in which roles and identities were managed alongside illness. This supports the earlier work of Fuchs et al. (2014) who found that sport enabled individuals to maintain or rebuild former identities as well as maintain physical capabilities as a way of taking control of the body. In this way, the authors found that sport became a disease management activity, a continuous process of adaptation and adjustment dependent on illness, which developed into a way of managing the physical, psychological, and social difficulties associated with illness over time. Here, I extend this previous literature which has offered points of connection between biographical disruption, the role of sport, and the psychosocial outcomes to further illuminate how the characteristics of social networks are impacted by these outcomes.

The network types that participants had in this study has contributed to previous research which has discovered similar types of networks with the addition of the diverse-sport focused network type. This finding contributes to the paucity of research that has determined the characteristics of transplant recipients' social networks. To my knowledge no research has discovered the types of transplant recipients' illness self-management networks and, as such, this study provides novel insights. Further, this finding has highlighted the impact of competing in Transplant Games events for the first time on the network types over a 12-month duration. In this way, this study makes an original contribution into the way participating in Transplant Games events may impact on illness self-management networks.

The diverse-sport focused network represented the impact of participating in Transplant Games events on the overall network type for a few participants. This supports research calling for local organisations to facilitate diverse networks which are easy to negotiate (Bossy, Knutsen, Rogers, & Foss, 2016; Jeffries et al., 2015; Portillo et al., 2015). For participants with diverse-sport focused networks, they had signified the importance of their Transplant Games contacts for their illness self-management. However, only a few participants had diverse-sport focused networks throughout the duration of the study and, as such, competing in Transplant Games events may not be impactful on the overall network type. This suggests that although attending the Transplant Games events impacted the network types of some of the participants, the Transplant Games members included within most participants' networks were considered weaker ties which therefore did not influence the overall type of network.

Overall, this finding makes a case for understanding the structure of participants' networks further, to illustrate the influence of weaker ties. Research has found support for community involvement such as the use of online communities which provided illness and emotional work (Allen et al., 2016, 2020). This research by Allen et al. (2016) found how community groups facilitate weaker ties and therefore provide opportunities to build diverse networks. In contributing to this research, I discovered that taking part in Transplant Games events did offer similar ways of facilitating weaker ties to that of online communities. However, whilst I found that weaker ties contributed to the diversity of networks, these ties did not necessarily alter the types of networks that transplant recipients had. In this way, the network types identified within this study are limited in their interpretation as they did not account for the role of weaker ties (Granovetter, 1977, 1983; Rogers et al., 2014). Although identifying network types may be useful, at a general level, in determining and identifying social ties (Wenger et al. 1996; Litwin and Landau, 2000) it is limited in the meanings it can attached to certain social network contacts such as peripheral network members. Future research may look to consider the classification of network types or look to establish ways to analyse the structure of social networks further to account for this.

8.3 Transplant Games events facilitated weaker ties implicit for illness self-management

A key finding within this study is how attending Transplant Games events for the first time, impacted transplant recipients' illness self-management networks. That is, Transplant Games

members that were included following attendance in Transplant Games events continued to be placed within participants' illness self-management networks for 12-months. However, the inclusion of the Transplant Games members were, for most, positioned on the peripheries of participants' illness self-management networks and were largely considered weaker ties. In this way, Transplant Games events facilitated weaker ties which could be explained in the context of illness self-management and the differences in the meanings attached to these weaker ties compared with stronger ties such as spouse, partners, and close family. According to research, weak ties are more durable (Rogers et al., 2014), require less effort to maintain (Fingerman, 2009) and can be sustained over time which can provide useful functions for illness self-management. Within this study, weaker ties provided useful functions with (1) buffering negative relational experiences of close ties, (2) offering an opportunity to share experiences and relatedness through automatic propinquity which promoted a sense of longevity, compassion and understanding. I will discuss both contributions of weak ties in turn, drawing on the social network findings and thematic findings whilst situating this within previous research.

Participants exhibited negative emotional experiences with their close ties following transplantation whereby most participants' close family, spouse or partner experienced anxiety associated with the lived experience of witnessing the deterioration of the health and the illness and transplantation journey of loved ones. Consistent with this finding, research has determined the negative influence of chronic illness on everyday interactions with informal support networks such as family members and close ties (Gallant et al., 2010; Gallant et al., 2007; Shaw. et al., 2013; Vassilev et al., 2014). Gallant et al. (2007) found these negative effects to be associated with family members being overprotective stemming from feelings of concern which impose a hinderance on individuals receiving the support. This is supported within this study finding in that the distress and trauma affected close tie support due to the proximity and emotional closeness of these individuals within participants' illness self-management networks.

This finding further contributes to the literature which has assessed the emotional impact of illness and transplantation on family members and caregivers (Walker, Naicker, Kara, & Palmer, 2019; Wicks, Milstead, Hathaway, & Cetingok, 1998; Wochna, 1997). Walker et al. (2019) found that parents' anxiety would be exacerbated when dealing with the uncertainty of their child's future health following transplantation. The authors suggested that clinical practice should evaluate the psychosocial components of family support which may

offer wider implications of the provision of informal support. Similarly, Brännström et al. (2007) found that loved ones providing support struggled with uncertainty and anxiety due to the threat of worsening health and trying to maintain normality of everyday life. This study finding further illuminates the work of Walker et al. (2019) and Brännström et al. (2007) in that anxiety and worry was presented in daily interactions which close tie support struggled to deal with. This ultimately impacted on the types of support participants would seek from their close ties. Thus, understanding close tie anxiety may help in determining effective strategies for participants to manage post-transplant outcomes within their informal networks.

Taking part in Transplant Games events facilitated the establishment of new weaker ties which offered a release from close tie support as individuals sought and gained emotional and everyday work from their weaker ties, usually other transplant recipients met through taking part in Transplant Games events. In this sense, weaker ties provided a buffering effect for participants when discussing their health concerns which therefore limited these types of interactions with close ties. Research considering the buffering hypothesis (Cohen, 1988; Cohen & Wills, 1985; Dean & Lin, 1977) may offer explanation for how weak ties gained through taking part in Transplant Games events buffer the negative experiences of close tie relationships. Often close ties were reported to be too close and subsequently weaker ties positioned further away in terms of emotional closeness were more suited to discussing health concerns and seeking emotional and everyday work. This has been widely supported by previous research (Brashers, Neidig, & Goldsmith, 2004; Dunkel-Schetter & Wortman, 1982; Wright, Rains, & Banas, 2010). Wright et al. (2010) found that when discussing health problems with close ties these conversations were steered away from emotional in-depth discussion of such health concerns and in some cases, limited interaction all together.

Despite this, participants often positioned their close ties centrally within their illness self-management network which was consistent over time. This supports the thematic analysis finding of *close tie anxiety* in several ways. Firstly, the anxiety that participants' close ties experienced was initially reported by participants due to the emotionally closeness of their close ties within their illness self-management networks. Secondly, the close tie anxiety did not seem to influence the perceived emotional closeness of these actors within the network. That is, the social network findings indicated that these actors remained very emotionally close and instead participants spoke about how they altered the way in which they shared information with these close ties when it came to discussing their health. Thus, promoting weaker ties for certain types of work to reduce discussions with close ties regarding their ongoing health.

Participants also discussed how their spouse or partner was considered the most important actor within their whole network. This may be explained in terms of the role obligations (Wright et al., 2010) whereby participants felt the need to include their spouse or partner centrally due to the role they have fulfilled throughout their illness and recovery. However, for some participants their spouse or partner had become less central over time as weaker ties established from the Transplant Games events, which were perceived as less emotionally close, were called upon for illness or emotional work. Within participants' networks, this was demonstrated in the connectedness of weaker ties over time. Although in most cases these weaker ties remained disconnected to participants' spouse or partner and were peripheral, which decentralised their role within the network. What can be established from this finding is that although Transplant Games actors may be perceived as important to illness self-management, these actors do not need to hold central roles within the network to be influential.

This finding provides validation for the network concept of the strength of weak ties (Granovetter, 1973, 1977, 1983) which is consistent with a wider body of literature determining the role of weaker ties in providing types of work with self-management outcomes of chronically ill populations (Allen et al., 2016; Crotty et al., 2015; Rogers et al., 2014; Vassilev et al., 2016). The negative emotional experiences of close ties were further negated by weaker ties as these ties were further removed in terms of dependency and intimacy. This is supported by Rogers et al. (2014) who suggested that weaker ties have been found to play more central roles with illness management as they resemble clearer reciprocal exchanges. This is further supported by research that has outlined the reciprocal nature of close tie relationships which can often lead to conflict and negative feelings (Wright et al., 2010). Further, the role obligations attributed to close tie relationships may complicate the support role and work offered by these ties. For example, recipients may feel a level of discomfort in not being able to reciprocate the support offered by their close ties (Adelman, Parks, & Albrecht, 1987; Albrecht & Goldsmith, 2003).

Although participants called on weaker ties to provide illness and emotional work, these ties remained weak over time and in most cases did not become integrated within the wider network. However, for some participants they had positioned Transplant Games actors centrally, the promotion of these weaker ties over time led to the formation of friendships which encouraged these actors towards more central roles within participants' networks. This also supports how automatic propinquity influences not only the inclusion of network members but

the position and perceived closeness of Transplant Games actors as participants manage the anxiety of their close ties.

This finding also extends research calling for a greater understanding of the negative experiences of illness on family members and close tie support (Vassilev, Rogers, Kennedy, Oatley, & James, 2019; Vassilev et al., 2016). Furthermore, research has called for interventions that integrate family members and primary caregivers as a way of reducing their worry and anxiety and to provide them with coping mechanisms to provide effective care (Lerret et al., 2020). Here, I extend this research by offering an alternative approach in taking part in Transplant Games events as a way for participants to cope with the negative emotional experiences of close ties. Furthermore, this finding answers Rogers et al. (2014) calls for research understanding how community-based involvement could facilitate weaker ties which in turn could provide individuals with the opportunity to build diverse networks which provide greater access to resources (Vassilev et al., 2013). It is clear that weaker ties gained through participation in Transplant Games events substituted close ties when called on for emotional and everyday work (Allen et al., 2016, 2020; Vassilev et al., 2013).

Finally, this finding may also offer a fruitful area for future research to extend. Future research may consider the potential impact Transplant Games events have on transplant recipients' family members and close ties who get an opportunity to share experiences with the family members and close ties of other transplant recipients. This may offer an understanding of the impact Transplant Games events on networks of care and may provide a suitable setting that integrates family members and primary caregivers. However, as Transplant Games events are not open to all it may be useful to consider alternative community-based involvement that could offer similar benefits such as various support groups.

Linked to how weak ties buffer the experiences of close tie anxiety is the finding of how these weak ties were formed through automatic propinquity. That is, the Transplant Games events offered opportunities for participants to meet similar others to share illness and transplantation experiences with, which formed automatic bonds. Forsberg et al. (2000) support the idea that shared experiences of survivorship act as a way of managing identity disruption and moves the illness and transplant experience away from being unique. The relatedness and closeness between transplant recipients developed through shared illness experience through competing in Transplant Games events, along with shared empathy and compassion established through lived bodily experiences created a sense of belonging, longevity, and togetherness. The

multi-layered identities of being a transplant recipient and enacting sport created a deeper and more meaningful connection. Although it was not always the reason for friendship and in some cases automatic propinquity acted as an initial way to develop relationships which were considered as weak ties within participants' networks.

This finding also contributes to the social comparison literature in that competing in Transplant Games events promoted an element of comparison whereby participants would compare their health and physical capabilities with others which often provided hope and inspiration and a future focus towards longevity of health. Helgeson and Gottlieb (2000) found social comparison to be integral to support groups. Further, interacting with a wider network at Transplant Games events offered an opportunity to meet similar others experiencing similar health concerns. In this way, interacting with a more diverse network promotes more opportunity for social comparison (Adelman et al., 1987). Some participants used this comparison as a way of positioning their health against others as a way of self-evaluation and assessment. This aligns with Ouellette et al. (2009) findings whereby participants engaged in social comparison as a way of normalising experiences. The authors found that this was positively perceived which is consistent with the findings of this study, providing a future focus on the advantages of current experiences.

Conversely, previous research has criticised self-management programmes which rely on social comparison to facilitate action. Rogers et al. (2009) argued that these programmes had not considered the negative impact social comparison may have such as upward comparisons which could cause emotional disruption (Gately et al., 2007). However, I found the use of social comparison between transplant recipients was not negatively perceived and as such did not induce the disruptive emotions previous research has highlighted. Instead, upward comparisons promoted a sense of longevity, hope, and inspiration where individuals developed bonds through their shared experiences. This is supported by Festinger (1954) social comparison theory which argued that upward comparisons encouraged striving behaviours and provided motivation to succeed, whereas downward comparisons could be ego-enhancing (Sitch & Lowry, 2019). This is further supported by the early work of Helgeson and Taylor (1993) where downward comparison was associated with better psychological adjustment and upward comparison provided feelings of hope and inspiration as well as information useful for improving individuals health condition.

Despite this, it may also be that the very nature of a sporting competition that ensures that those taking part will always have upward comparators available. In this way, Transplant

Games events may offer social comparisons which are positively perceived due to competitors having to be well enough to take part in Transplant Games events in the first place. Thus, the positively perceived social comparisons may not be extended to other community-based support groups.

Automatic propinquity is reinforced by previous research understanding the social bonds between similar others who had experienced suffering (Ketokivi, 2009; Ketokivi & Meskus, 2015). Ketokivi (2009) found that through common experience, bonds could be formed. Further, the authors found that individual experiences which were not relatable to significant others promoted the search for similar experiences in others in new social contexts. Within this study, the new social context represented Transplant Games events where automatic propinquity promoted the discovery of similar others which represented weaker ties within individuals illness self-management networks. Here, this bonding allows for the lived experience to be shared with others which according to Ketokivi and Meskus (2015) can reduce the burden of the disruption. Furthermore, as Charmaz (1983) found, those who experience suffering may experience a loss of self if there existed no opportunity for social validation.

These findings support the current study in that automatic propinquity developed through participating in Transplant Games events became an important way for participants to manage disruption to their self, body, and identity whilst shared experiences normalised this disruption and provided a future focus. Further support for this theme comes from well-established network research which has demonstrated how networks are constructed through a process of selecting similar others over time. Similarity between ties are often preferred and are more likely sustained over time which creates a homophilous network (McPherson, Smith-Lovin, & Cook, 2001). Yet, within this study, automatic propinquity promoted the inclusion of weak ties and, although sustained over time, these ties remained weak and did not create a homophilous illness self-management network. Transplant Games actors were represented as either separate regions or they were integrated within other regions which held various relationships. Further, some participants' networks displayed isolated or dyadic representations of Transplant Games actors which were not part of any regions. Over time, the Transplant Games regions either became integrated within other core regions or these regions diminished on the peripheries operating as separate spatial zones.

The Transplant Games regions represented within participants' networks provide support for automatic propinquity in that participants who shared illness and transplantation experiences with others as they negotiated transliminality felt an immediate bond promoting

the inclusion of actors which formed specific regions within participants' social networks. However, not all the participants had represented specific Transplant Games regions within their networks and the inclusion of Transplant Games regions did not influence the overall density of participants' networks. This reinforces automatic propinquity in that some participants determined discrepancies between different types of transplants, experiencing a closeness only with those that had the same transplant. This provides further support for research outlining how similar others are likely to form bonds, creating homophilous networks (McPherson et al., 2001). In this case, participants did not include a Transplant Games region as such, instead their network represented individual Transplant Games actors positioned as either isolated or dyadic relationships with which they shared similarities with. These relationships became integrated within other network regions over time.

Overall, automatic propinquity can only partly explain the inclusion of Transplant Games actors. Given that participants' networks were influenced by their participation in Transplant Games events and by their transliminal health - which impacted on their ability to take part in sport - automatic propinquity may be one of several contributing factors influencing changes in the size, structure, and function of participants' social networks regarding the inclusion of weaker ties. However, this finding does contribute to the existing knowledge on the homophily within networks and provides further validation through the way in which participants spoke of these automatic bonds with each other.

8.4 Participants perceived that participating in Transplant Games events positively impacted their illness self-management

The findings of the present study point towards how participating in Transplant Games events impacted on participants' illness self-management through prompting them to re-examine the extent to which they felt themselves to be in-between healthy and being ill. Re-examining one's position between illness and health often meant constructing identities and coming to terms with new social roles which influenced the construction of illness self-management networks. Transplant recipients engaged in Transplant Games events which offered an opportunity to obtain a social status which was connected to how they managed ongoing fluctuations between illness and health. Negotiating transliminality through sport determined how participants came to terms with their transliminal self through proactive action of taking part in Transplant Games

events. This was also evident in how participants spoke about the transformative experiences of taking part in Transplant Games events in that participants in this study used participating in Transplant Games events to position their identity towards being healthy, acknowledging the transliminal self and becoming aware of mortality and the unique experiences they faced as they moved through life post-transplant. Participants' experiences of transliminality were for most, embedded within their identities and for some, sport offered a way to enact a healthy identity and participation in Transplant Games events reinforced this identity through becoming and accepting the role of being a 'transplant athlete'. These findings contribute to the literature in several ways.

Firstly, this finding extends previous research that has illuminated how identity is continuously positioned as a transplant recipient. Svenaeus (2012) found that the illness experience and receiving a transplant impacted on identity which influenced changes on the embodied level and existential self-reflection level. The idea that illness experiences influence identity tie into the challenges outlined by Aujoulat et al. (2014) and Ouellette et al. (2009) where chronic illness and transplantation require a level of negotiation in order to resume normal functioning and integration into normal life. Aujoulat et al. (2014) determined the success of self-care on the illness experience emphasising the importance on individuals' self-definition and sense of self which ultimately impacts on self-management outcomes. In agreement, Ouellette et al. (2009) found that individuals are challenged with integrating their illness within their identity and reality of daily life. Conversely, transliminality presented within this study is more in line with Crowley-Matoka's (2005) conceptualisation of liminality which extends beyond the transitional perspectives to describe the complicated less binary journey through rite of passage. This is further supported by the work of Bogue Kerr et al. (2018) where transplant recipients negotiated the liminal space to come to terms with their transliminal self, where individuals are deeply aware of their mortality but are never fully healed. This is true for the participants in this current study as they often reflected on mortality and being between sickness and health through their experiences of participating in Transplant Games events. Bogue Kerr et al. (2018) determined transplant recipients' experiences across stages of liminality, separation, transition, and integration. This study extends this previous research by highlighting how Transplant Games events allowed individuals to discover and make sense of their own transliminal space.

Furthermore, this finding contributes to recent research on the topic of identity in the work of Cormier et al. (2017). Here, the authors found that transplant recipients' identity

changed through the transplant experience. The authors conceptualised this as the new transplanted self which represented the transformative journey of individual identity. As participants dealt with the fluid liminal space between illness and health, sport was used as a way of positioning a stable sense of health and in some cases a way of shaping and constructing sporting identities which became a continuous process that involves both medical and social worlds. In constructing these identities participants also constructed their networks to reflect their new identity and positioning.

Finally, I extend previous literature by demonstrating how sport acted as a vehicle for navigating transliminality. It was navigating the new social roles that taking part in Transplant Games events offered which often shaped the new transplanted self and transplant recipient as an athlete. Research has found support that sport involvement is associated with the development and maintenance of social relationships (McDonough et al., 2018). Although how these social relationships are positioned within participants' social network structures over time may influence illness self-management outcomes, identity and transliminality which, up until now, has been largely unexplored. As participants' social networks reflected their illness self-management, the importance of Transplant Games actors in influencing transliminality supports the finding that social networks are constructed as part of constructing new roles and identities which forms part of illness self-management practices.

My findings also align with research signifying the importance of the relationship between recipients and their donor. That is, the gratitude transplant recipients experience having received a transplant influences their reciprocating behaviours through paying it forward or influences feeling of guilt for being kept alive which in turn informs participants' actions. Participants' reciprocal behaviours experienced as they moved through their transplant trajectory aligns with Wainwright (1995) final stage of the transplant trajectory concerning the reciprocating phase. Participants' gratitude promoted the need to give something back as a coping mechanism for receiving the ultimate 'gift of life'. This finding also agrees with Fox and Swazey (2002) who conceptualised the 'tyranny of the gift' to describe the complicated process of receiving an organ transplant. The authors found that the rhetoric around receiving a transplant was centred on the gift of life which promoted gratuitous behaviours which became imbedded in individuals motivations to enact certain behaviours post-transplant as a way of acknowledging the indebtedness they felt (O'Brien et al., 2014; Sharp, 2006; Sque & Payne, 1994). In this sense, I extend these findings by showing how Transplant Games events becomes a way of demonstrating these behaviours.

An important contribution to the literature worth noting here was that participants in this study often looked to pay it forward as a way of moving beyond the indebtedness they felt as they experienced both positive and negative emotional responses to this. Those who had received an organ from a deceased donor often experienced survivors' guilt as they questioned their deservingness of receiving a transplant as they came to terms with the loss of others life for the prolongment of their own. In support of previous research this finding supports the work of Ummel and Achille (2016) who found the obligation to give back more present in recipients who received an organ from a casual rather than family relation as family relations often already held reciprocal and ordinary kinship obligations. For participants who had received a live altruistic donation, they had included their donor within their social network as a way of demonstrating gratitude towards them. These donor actors, which often represented either close family, spouse/partner, or friends, were often perceived as very emotionally close, positioned centrally within participants' networks which was consistent over time. Often participants who received an organ from a deceased donor wanted to include their donor in their network but found it difficult to make sense of this to do so. This further highlights the complicated nature of organ donation and extends previous research by highlighting how the construction of illness self-management networks become integral to making sense of this.

The positive emotional experiences included behaviours such as promoting and raising awareness for organ donation or being a 'good recipient', enacting healthy behaviours. These behaviours often provided participants with a way of dealing with survivors' guilt. This resonated with O'Brien et al. (2014) study findings in that the positive and negative emotional responses, where paying it forward provided an opportunity to manage the negative emotions associated with reciprocity. The authors found that participants joined support groups to assist others through similar health concerns which also aligns with the earlier work of Wood et al. (2008) who demonstrated that gratitude increased participants' social functioning when positively perceived. Comparisons can be drawn between these findings and how participating in Transplant Games events offered a way for participants to demonstrate gratitude and manage the survivors' guilt and obligation to pay it forward. Further, meeting other recipients often reinforced these beliefs which often confirmed and promoted dutiful behaviour and, in some cases, continued participation in future Transplant Games events. That is, gratitude and pay it forward may spread through social networks promoting upstream reciprocity (Nowak & Roch, 2007) or generalised reciprocity (Barta, McNamara, Huszar, & Taborsky, 2011). This cooperative behaviour promoted from receiving a transplant creates a cascade of kindness in

returning favours to others. This can be explained simply in terms of those who have been helped are more willing to help others (Bartlett & DeSteno, 2006; Christakis & Fowler, 2009). Social network members are likely to influence choices individuals make and these members are also likely to reinforce those choices. Research has also determined this as contagion whereby individuals replicate and model their practices through others (Christakis & Fowler, 2007; Friedkin, 2006; Kennedy, Vassilev, James, & Rogers, 2015). This may further explain how gratitude, survivors' guilt, and obligation to pay it forward is spread through establishing relationships with other individuals met through Transplant Games events. Here, meeting others at Transplant Games events further reinforces motivations to taking part. This study further illuminates how this evolves over time and the prosocial behaviours become embedded into the everyday lives of transplant recipients.

Although this study has illuminated how this prosocial behaviour may positively influence sport participation, caution is warranted when determining the positive influence of participating in Transplant Games events as the findings also exhibited negative feelings of guilt when participants could not continue their participation in Transplant Games events due to physical limitations or health decline. This may raise concerns that taking part in Transplant Games events becomes imbedded in the already existing and multiple obligations transplant recipients deal with, which may move participation in the Games away from an illness self-management practice towards inducing further distress when participation is not possible. Future research is warranted to further understand how reciprocity is spread through sport-based networks and how this may impact on commitment and motivation to continued participation.

8.5 Implications

I am dedicated to discussing the relevance of this study for transplant recipients' self-management. Within this following section, I outline the implication of moving beyond the 'self' in self-management programmes and I reaffirm the place for social network interventions for transplant recipients. I will then discuss the implication of how sport may be used as a tool for improving psychosocial functioning important for better health and self-management outcomes. In moving towards the question of 'so what?' I will highlight the challenges of this

research whilst being cautious of its implications. In doing so, I will offer tentative connections to what might be learnt from the findings of this study.

8.5.1 Moving beyond the 'self' in self-management

This study has highlighted how living with a transplant and managing illness not only shapes social relationships, but it involves a continual management of the concerns and expectations network members may hold as well as adapting to changing roles and responsibilities. In this sense, self-management requires an awareness of how to manage social relations which offer important support post-transplant. Therefore, transplant illness management needs to move beyond the self and individual level focus to understand the wider social context and the importance of social networks which contain network members who offer support for self-management outcomes. This sits in line with previous research who have echoed these calls (Jeffries et al., 2015; Morris et al., 2016; Vassilev et al., 2014; Vassilev et al., 2011). In doing so, practitioners should consider both the positive and negative impact social networks may have towards self-management outcomes.

Understanding the various types of social networks offers an understanding as to why polices and education programmes that are situated as a one size fits all approach are unable to address the imbalance in the utilisation of these programmes such as the Expert Patient Programme (Newbould, Taylor, & Bury, 2006). Further, in discussing the different types of networks, programmes could be tailored to the changes in support required over time. For example, identifying family-focused networks may be useful when determining interventions for illness management if individuals require support from certain family members which may also be dependent on other factors such as their age (Stoller & Wisniewski, 2003) or strength of relationship. Here, interventions focused on families such as identifying family relations barriers to providing support or educating family members on coping mechanisms and communication skills, may be useful in facilitating self-management. Previous research has determined how a focus on family interventions may expedite illness management support (Rosland et al., 2010). As such, identifying family-focused networks can help determine the interventions most suitable to facilitating illness management for transplant recipients. Future patient support programmes could focus on enhancing diverse network types for optimal self-management for transplant recipients or could encourage the facilitation of weaker ties which

may provide important support. Furthermore, understanding network types may be useful for practitioners in understanding the interpersonal milieu with which transplant recipients are situated and function within. Knowledge of network type assessments and recognising how this shifts over time may be a beneficial way of determining the efficacy of interventions and may serve as a basis for risk assessment.

The social network approach this study adopted, utilising the sociogram creation task during interviews, was a useful tool. The sociogram task acted as an intervention, opening dialogue which assisted in transplant recipients' discovery of their personal social networks important for their illness self-management. This task also offered an opportunity to challenge participants on understanding their ongoing and changing support needs. Previous intervention research has provided support for a social network mapping exercise that promotes the discovery of social network members, educating transplant recipients on how to engage with their social network for support and management purposes (Chang, Winsett, Osama Gaber, & Hathaway, 2004; Lewis., Winsett, Cetingok, Martin, & Hathaway, 2000). Furthermore, wider health research that has assessed the use of social network interventions with people with long-term conditions has found that through intervention engagement several benefits could be derived (Vassilev, Rogers, et al., 2019).

This prompted the development of a social network tool - GENIE (Generating Engagement in Network Involvement) - as an intervention which co-produces personal networks following a similar network mapping exercise outlined in this study (Kennedy et al., 2015). Results have indicated that the GENIE intervention diversified participants' networks which led to greater involvement in community activities positively impacting quality of life (Welch, Orlando, Lin, Vassilev, & Rogers, 2020). Similarly, James, Kennedy, Vassilev, Ellis, and Rogers (2020) found that the GENIE intervention which consisted of the visualisation of social networks helped individuals reflect on their network and reconstruct their self-management support which also enabled the prioritisation of certain network members. The focus away from the self and towards the wider social world enabled a broader approach to self-management. Whilst this study does not propose a social network intervention such as GENIE, it does offer implications for future practitioners in understanding the potential feasibility of social network interventions and the willingness of transplant populations to engage with the sociogram task. Further, this study hopes to illuminate through the depth of

the findings how this approach may offer an alternative to elicit meanings of relationships important for self-management.

Social network interventions can impact on the structure of social networks (Kennedy et al., 2015). However, changes to the structure of networks may be more nuanced requiring a deeper level understanding of the meanings attributed to this change. It is important to note that future interventions should also consider the burden of dealing with relationships in order for these programmes to be effective (Vassilev et al., 2014; Vassilev et al., 2016). Whilst the 'self' in self-management may explain the individual level behaviours required in managing post-transplant outcomes, programmes must broaden this to include the wider and much more complex social components. These future interventions should also consider the role of illness work from a social context to understand how relationships may influence this (Rogers et al., 2009). Further, practitioners should seek to explore the deeper meanings attached to social relationships and informal networks when determining approaches that move away from formal healthcare settings and should consider the negative impact of these relationships on transitioning to self-care or when navigating the various roles and responsibilities in moving towards normal functioning. Although individuals' personal networks may seem stable on the surface, a deeper level understanding of the quality and meanings attached may benefit future interventions.

8.5.2 Sport as a psychosocial tool

This study has clearly demonstrated how network members gained through participation in Transplant Games events impact illness self-management by providing types of support which positively influences perceived support and wellbeing. Therefore, sport offers an opportunity to build social networks which are therefore beneficial to health and illness management outcomes. Brandling & House (2009) suggested that social activities such as dance have been recommended by GPs to improve wellbeing. Despite this, the authors found that supportive frameworks and mechanisms have not been put in place which meant these suggestions remained tokenistic (Brandling & House, 2009). Research has also demonstrated how sport could be used as a way of managing the trajectory of transplantation and chronic illness as a way of improving physical, psychological, and social outcomes (Bobrowski, 2020; Fuchs et al., 2014; Le Hénaff & Héas, 2020). Furthermore, research has indicated that sport should be

promoted within these populations and recommend participating in sporting community events such as the Transplant Games post-transplantation (Wray & Lunnon-Wood, 2008). This study extends these recommendations by highlighting the role of sport in the form of participation in Transplant Games events which contributes to the illness self-management of transplant recipients. Moreover, as there exists scant research which has emphasised the social context of taking part in sport and Transplant Games events from a social network perspective this study further contributes to literature by addressing this gap, moving towards understanding the potential impact of sport as a psychosocial tool. In doing so, this study offers future policy makers and practitioners with evidence of the psychosocial impact of sport that moves beyond the well-established physiological benefits. Further, I would encourage future practitioners to consider sport from a psychosocial perspective as a potential tool to aid self-management and rehabilitation.

Bobrowski (2020) found sport to be a useful tool in improving psychosocial outcomes such as quality of life and mental health. Further, the authors found sport useful as a resource for managing illness and transition to normal life and a way to increase socialisation. However, the authors only partially make connections between sport and increased social functioning and as such are limited on the reach of these claims. However, this study has illuminated the social context of sport which is essential to the return of normal social life. Cho et al. (2017) acknowledged how the Transplant Games were developed for recipients to improve and build friendships. In this way, I have demonstrated how the Transplant Games events can facilitate social networks in a meaningful way which may in turn reduce the burden on health professionals as well as move beyond the individual level focus.

Despite the clear links, sport interventions for transplant recipients remain scarce. Furthermore, understanding how the long-term impact of prolonged participation in sport may sustain these benefits is under researched. Therefore, the longitudinal perspective of this study offers a way to understand the impact of sport over time. Given the increase in frequency of transplant procedures and medical advancements, which have prolonged the longevity of transplants, there is a growing population of transplant recipients navigating life post-transplant. Sport may offer a useful tool to navigate the life course post-transplant which this study has demonstrated. Furthermore, the positive experiences associated with participating in Transplant Games events are wide-reaching. That is, participating in Transplant Games events can impact across all types of transplant recipients and can positively impact on both

individuals who have recently received a transplant or those transplanted several years ago. Consequently, practitioners may promote the use of sport post-transplant and encourage the prolongment of such initiatives on the basis that the impacts are long-lasting. For example, the international initiative *Refit for Life!* (World Transplant Games Federation, 2019) which offers a rehabilitation programme for transplant recipients emerging from hospital to increase their activity levels and wellbeing would be supported by the findings of this study.

This study adds to our understanding of how sport becomes part of the dynamic nature of participants' social networks. The active participation in sport with similar others that is facilitated by taking part in the Transplant Games events helps individuals to position their networks either towards health or towards illness. In this way, negotiating transliminality in a physical sense could be easily positioned against physical capabilities during sport, something not so easily understood in other community groups perhaps. This is true for how participants discussed discovering their physical capabilities through sport. However, future policy makers and practitioners should carefully consider how individuals position themselves in terms of their health and illness and how individuals attach their motivations to competing in sport.

Caution is warranted with recommending sport as a psychosocial tool as participation in sport may not be a viable option for all and some transplant recipients may not wish to take part in sporting competitions such as Transplant Games events. Moreover, some may wish to take part but not for the intended positive outcomes outlined within this study. The positive outcomes this study outlined may also be facilitated through other ways at a more local level which does not encompass Transplant Games events such as other charities or community-based events. However, given the focus on sport and Transplant Games events within this study, the positive outcomes are wide-reaching.

This study found that sport may reinforce notions of taking part in Transplant Games events as a way of giving back through promoting organ donation, expressing gratitude towards donors and as a way of helping others. However, understanding the wider implications of these motivations may ensure that when sport is encouraged on the grounds of enhancing psychosocial outcomes towards illness management, that it does not cause adverse negative effects such as distress or guilt for not competing in Transplant Games events for individuals who are unable to. I suggest that when determining interventions and sport initiatives for transplant recipients to consider the impact of individuals' fluctuating health on their ability to enact sport which may impact on the prolonged feasibility of such sport initiatives. Therefore,

a degree of flexibility is warranted when considering such interventions. However, based on the evidence presented within this study, sport can offer a useful tool for facilitating transplant recipients' illness self-management networks.

8.6 Methodological Contributions

I have drawn on methods that have been applied across other fields of study, which are established methodologies in themselves yet, novel in their application to this setting. In determining the methodological contributions, I will examine and outline the strengths and limitations of this methodological approach to further illuminate its appropriateness and potential shortfalls which may contribute to the wider application of qualitative longitudinal social network research.

8.6.1 Longitudinal social network research

In this study I have responded to calls from research to assess the longitudinal aspects of social networks to understand the dynamic changes within and across networks over time. To my knowledge, this study was the first to map transplant recipients' personal social networks over a 12-month duration. Mapping participants' illness self-management networks over time in this way, I have demonstrated how the information gained at each phase has contributed to richness in the data which is a strength of this study. Further, this study has provided an example of the feasibility of conducting longitudinal social network research. The longitudinal approach has allowed for an in depth understanding of how relationships and meanings attached to relations remained the same or changed over time. The longitudinal design also gave me an opportunity to develop rapport with the participants through their prolonged engagement with this study, which provided richer and more detailed accounts of their experiences (Barbour, 2008).

This study implemented time boundaries across the 12-month longitudinal design whereby the longitudinal interviews and sociogram creation tasks were separated by 6-month intervals. This was considered most appropriate in terms of the feasibility of the study and to limit participant burden across the 12-month study duration. Considering different time

boundaries between phases may have elicited varied responses from participants. For example, some of the participants' health had declined between interview timepoints which may have elicited varied responses dependent on when the interviews took place after health decline was experienced. Furthermore, a key finding of this study was how transplant recipients moved between illness and health over time, which may have impacted on how participants responded to both the interview and sociogram creation task. Research has suggested that taking a more flexible approach to the interview timepoints may offer greater insight into the unpredictability of participants' illness trajectory (Carduff, Murray, & Kendall, 2015; Nissim, Gagliese, & Rodin, 2009). Future research should consider the time sensitivity of interview boundaries carefully, beyond feasibility and participant burden, and may wish to consider introducing regular telephone contact to act as 'catch up points' between interviews.

Likewise, time since transplant was not considered from the outset of this study which may have an impact on individuals and their self-management outcomes. Moreover, time since the transplant may have impacted on how transplant recipients defined their roles and identities which may influenced how and why they engaged in Transplant Games events and took part in this study. Although, it was thought that as self-management is not a linear process, the impact of time on the ability for participants to build illness self-management networks would not be time critical. Further, as participants were taking part in their first Transplant Games event, they may have already assumed roles and identities away from being a patient or ill person. Previous research has provided support for how quality of life was not impacted by time since transplant (Mazzoni et al., 2014; Ponton, Rupolo, Marchini, Feltrin, & Perin, 2001) and as such the variation between participants' time since transplant was not considered detrimental to the findings of this study. However, future research may wish to consider time since transplant and how this may impact on sports participation. Specifically, research may look to establish how time since transplant influences transplant recipients initial and continued engagement with Transplant Games events and the impact this may have on their illness self-management networks.

8.6.2 Qualitative social network approach within sport research

Within this study, I utilised qualitative social network methods in the use of the sociogram creation task during interviews. The sociograms were analysed using visual network analysis

which considered the topological dimensions of network structure. This approach integrated the interview data to capture the dynamic interplay between how the structure of networks were visualised and how individuals spoke of them. Across wider social network research in sport, social network research has largely been quantitative, descriptive and to some extent exploratory in nature. This is in part due to the infancy of social network approaches being applied within sport literature. However, research further afield has moved towards combining mixed method approaches introducing interviews alongside formal social network methods to gain an insider view (Paisley et al., 2014) or to identify culture and meaning of social worlds (Katz & Heere, 2013, 2015). Research has also used participant-aided sociograms as a tool to elicit deeper relational conversations, for example Poucher, Tamminen, and Kerr's (2018) Olympic athletes social support study.

Contrary to these advancements, qualitative social network approaches within sport have not yet been applied systematically despite calls for researchers to step out of the boundaries of well-known, widely prescribed and utilised methods towards broader methods of data collection (Sparkes & Smith, 2013). As such, there remains a paucity of research outlining and conducting coherent qualitative social network approaches. Further there is a lack of research critically assessing the quality of current qualitative approaches to network analysis. One major criticism led by Diaz-Bone (2007) is that qualitative social network research is problematic in that research has labelled qualitative approaches to network analysis when conducting mixed method approaches which do not fulfil qualitative research. Herz, Peters, and Truschkat (2014, p. 6) stated that; "this lack of systematic discussion on methods for analysing data when carrying out qualitative network analysis means that the criticism levied by Diaz-bone (2007) at the qualitative forms of network research remains pertinent". Scant research has addressed these criticisms or provided detailed and transparent approaches to progress these methodological conversations up until now. Further, it is difficult to assess the quality of such research to date when approaches have been far from systematic or detailed enough for replication and critique. The hope is that this PhD study will contribute to the development of qualitative social network research further in offering a detailed account for replication and an honest reflection on the methodological challenges, whilst also offering key learnings to further open the dialogue in refining and developing methodologically sound approaches.

Hollstein (2011) assessed the applicability of a qualitative approach to social network research and outlined two key components. Firstly, a qualitative approach to social network

research would explicate the problem of agency. As White (1992) stated "agency is the dynamic face of networks" (White, 1992, p. 315). Secondly, qualitative approaches offer the means to address questions relating to the dynamic nature and constitution of networks. White explains; "social networks are phenomenological realities, as well as measurement constructs. Stories describe the ties in networks…A social network is a network of meanings" (White, 1992, pp. 65, 67). A key methodological contribution of this study has been to outline what a qualitative social network approach looks like so that other researchers might better understand how qualitative social network data is collected, analysed, and presented.

In carrying out a complex multi-method approach with transplant recipients, I have not only demonstrated the viability of such methods with a transplant population, but I have also highlighted the meaningfulness in this approach. The combination of interview data with the structural components of participants' social networks created a dynamic 'whole picture' of depth and meaning through the constant interplay between the narrative accounts and the network visualisations. The qualitative data enhanced the network data and vice versa, demonstrating the power in telling stories about relationships important for illness self-management. The social network data captures a static version of interactions and, as such, the nature of the visualisations should be considered dynamic and continuously changing. Further, when determining differences or similarities across and between participants' social networks, the narratives help in providing a more complete view of participants' networks impacted through participating in Transplant Games events.

In outlining a detailed qualitative social network approach, this study may act as a resource to draw from when making strategic choices on data collection methods and types of analysis. Previous research has suggested that qualitative social network research needs to provide clarity on its approach if it is to accomplish what social network research in other domains have done (Hollstein, 2007, 2011). This study offers clarity in the qualitative social network approach to enhance the application of these methods for future research. Additionally, I hope to have provided a guide in which to inform researchers within sport domains, considering qualitative approaches to social network research, to think critically about their approach to data collection and analysis. Moreover, I wanted to demonstrate how a qualitative social network approach offers an alternative toolset for sport research to uncover meanings within relationships and network structures that could lead to development of new questions centred around structure and agency. However, while qualitative social network approaches may offer an alternative method within the qualitative toolset, along with new

questions, it must be considered carefully. When deciding on data collection and analysis methods, this needs to be informed, principled and based on the research question, it should not just follow the trends of time.

8.7 Limitations

A key consideration when interpreting the contributions and implications of this study is the risk of generalisability. This study may have illuminated the overarching positive experiences of engaging in Transplant Games events and may have unintentionally excluded people who have had problematic experiences with Transplant Games events. This may have included individuals who were unable to take part in Transplant Games events due to worsening health conditions or individuals who may be less connected to Transplant Games networks to find out about taking part in the study in the first place. Further, the participants within this study may have fundamentally different networks and transplant and self-management experiences from other transplant recipients or chronically ill populations which further limits the extent to which the findings of this study can be applied. Another consideration is how the findings may overemphasise the significance of sport given the focus on Transplant Games events and as such should be considered with caution.

One limitation of this study was that the purposeful sampling achieved through proactive recruitment of participants through Transplant Sport UK and World Transplant Games Federation may have excluded individuals that were not well connected to both these organisations. As this study was about the illness self-management networks of transplant recipients, the sampling strategy may also have excluded those that had smaller restricted networks. In this way, the participants that were included in this study may have been well connected and had established illness self-management networks. Further, the sampling strategy may have also unintentionally excluded individuals thinking about taking part in sport and Transplant Games events or those that had taken part in multiple Transplant Games events. However, as this study was concerned with first time participation and how this impacted participants' illness self-management networks over 12-month duration, it was thought the sampling accurately represented the aim of this thesis.

Another limitation may be the overarching focus on the positive outcomes of participating in Transplant Games events. Participating in Transplant Games events may have caused potential negative impacts on individuals and their illness self-management networks. This may have included experiencing more grief due to seeing others chronically ill participating in Transplant Games events or the death of teammates or fellow competitors. Further, illness self-management networks may facilitate ill-informed knowledge and advice about self-management and the networks built through participating in Transplant Games events may influence negative health expectations through social comparisons. Future research is needed to establish links with the potential negative outcomes of participating in sporting competitions such as Transplant Games events for transplant recipients.

Finally, this study did not consider the variations across transplant types and as such it may be important to further understand how transplant recipients' experiences of sport vary across transplant type. For example, heart transplant recipients may have a different experience to that of kidney or liver transplant recipients. Research is warranted to further examine the social bonds between different transplant types to better understand if those with the same transplant type form closer bonds due to their similar illness experiences and relatedness. Further, research is warranted to understand how different transplant types may impact on individuals' illness self-management networks.

8.8 Summary

This chapter has summarised and put into context the key findings of this study in relation to previous literature. I have outlined the influence of network types on illness management across a transplant recipient population, extending previous research. I also highlighted how Transplant Games events facilitated weaker ties which were impactful on individuals illness self-management. Moreover, I demonstrated how participants positively perceived their participation in Transplant Games events on their illness self-management. Finally, within this chapter, I have considered the wider contributions, implications, and limitations of this study to offer areas of improvement for future research. The next chapter will provide an overall conclusion for this thesis.

CHAPTER 9: CONCLUSION

In this final chapter, I will summarise the thesis and offer some reflexive comments about the study in its entirety whilst also providing suggestions for future research. This is important because the knowledge produced within this thesis may have been a result of the methodological and theoretical decisions I made, including the use of multiple methods situated within a qualitative longitudinal design.

Within this study I set out to show the value of investigating, exploring, and assessing the illness self-management networks of transplant recipients and their experiences of competing in Transplant Games events for the first time. Whilst the results are presented in separate chapters and answer specific research questions, they contribute to the overarching aims of this thesis. Further, the content of each results chapter, although presented separately, are interconnected in ways which does not make them distinct or sequential. In making this point, I hope I have been able to clarify ways in which qualitative social network research is combined and discussed to help inform future research. Given the lack of formal guidance in the combination of social network data and interview data, I hope to have offered insight into a multiple method approach and how it may be achieved within data collection, interpretation, and discussion. Future research is required to explore the combination of these types of data and how this is analysed and discussed to further enhance the tools for future researchers to achieve best practice. In returning to the research questions, I will offer conclusions to this empirical study.

Within Chapter 4, I presented the characteristics including the types of transplant recipients' social networks who had competed in the Transplant Games events for the first time. This chapter addressed the research question; *What characterises the illness self-management networks of transplant recipients who have participated in the Transplant Games for the first time?* In doing so, I identified the size and characteristics of participants' illness self-management networks and described the types of networks which reflected the interaction of various actors including family, friends, medical support, and other Transplant Games participants. The types of networks were generated using visual network analysis. That is, through the identification of the size and topological dimensions – which included the regions, centres, density, interfaces, and infrastructure of participants' networks – and their perceived importance based on the qualitative accounts, networks were categorised as one of four network types. These types included family-focused networks, friend-focused networks, family-friend-focused networks, and diverse-sport-focused networks. In determining the network types, I was able to distinguish between participants' networks and classify the

influence of Transplant Games actors in influencing the overall types of networks. The purpose of this was to determine how illness self-management networks were represented and how participating in the Transplant Games for the first time influenced the size and types of networks. I found that the relatively recent introduction of Transplant Games actors into participants' networks did not significantly alter their overall network types, apart from in the few cases where Transplant Games actors were perceived as very close. Most participants represented either family-focused or friend-focused networks and these two types were most stable across phase 1 and phase 3.

Within Chapter 5, I identified and presented the longitudinal aspects of participants' social networks using visual network analysis. This results chapter addressed the research question; *How do the illness self-management networks of transplant recipients who have participated in the Transplant Games for the first time change over the 12-months following the Transplant Games?* Findings highlighted the nature of the relationships considered important to transplant recipients' illness self-management and the dynamic interplay between the value attributed to different types of network members and the influence this has on the structure of the networks over time. I identified the impact of the Transplant Games actors on the topological dimensions of participants' networks which included the broader structural components including the regions, centres, density, interfaces, and infrastructure of networks. I found that participants who had attended Transplant Games events for the first time had included network members whom they had met at the Games. These network members continued to be placed within participants' illness self-management networks across the 12-month study duration. However, in most cases, these network members were weaker ties and remained as weaker ties over time.

In combining the visual interpretations of participant social network with the qualitative explanations from the interviews I was able to illuminate how participants spoke about and made sense of their networks over time. Research has been limited in offering insight into the network properties of individuals managing chronic illness (Rogers et al., 2011) and no research to my knowledge has been conducted with transplant recipient populations. Furthermore, identifying network structures has been somewhat limited within health research towards reductionism, whereby emphasis has been placed on the specificity of social ties and relationship types, at the cost of understanding the wider view of the network and its construction as a whole (Smith & Christakis, 2008). The strength of identifying the longitudinal aspects of participants' social networks was in the continuous oscillation between the structural

network components and the interviews. This enabled me to account for the dynamic nature of networks and to reflect on the temporal nature of social relationships considering both the perceived and received support.

Chapter 6 presented the results from the thematic analysis of the 48 interviews across the three phases of this 12-month study. The purpose of the thematic analysis was to answer the research question; *Why does taking part in the Transplant Games impact illness self-management networks?* The thematic analysis produced four themes. The first theme, *close tie anxiety* detailed the negative relational experiences in anxiety and worry that participants' close support network endured throughout their illness and transplant trajectory. This encouraged the agency of weaker ties, promoted through competing in Transplant Games events because Transplant Games actors were called on for support with illness and emotional work. These Transplant Games actors provided a buffer for the negative relational experiences and became a useful support source within participants' illness self-management networks. The second theme, *automatic propinquity* considered how closeness and relatedness between transplant recipients developed through shared experiences of similar illnesses facilitated through competing in Transplant Games events. The closeness between recipients was further reinforced through shared identities and similar interests which provided an explanation for why participating in Transplant Games events influenced participants' networks. The third theme of *negotiating transliminality through sport* explored how participants constructed their experiences of health and illness through participating in the Transplant Games which influenced their illness self-management networks. The fourth theme, *gratitude, survivors' guilt, and obligation to pay it forward* resembled participants' appreciation for a second chance at life. This promoted survivors' guilt for being kept alive which influenced participants' notions of giving something back through raising awareness and taking part in the Transplant Games. Transplant Games actors met through the Games events included within participants' networks often reinforced these behaviours and reconfirmed participants' gratitude and obligation to give back.

In Chapter 7, I presented the longitudinal component of the thematic analysis which consisted of the sequential matrices which enabled the creation of summaries for each theme across participants' three interviews. This chapter addressed the research question; *How do these factors change over the 12-months following participation in the Transplant Games?* I presented the summaries of the changes across each of the themes alongside individual case studies to provide an in-depth analysis of the longitudinal changes over time to understand

participants' experiences over the 12-months following their first Transplant Games. The participant case studies although individually unique, offered insights which could be applied to other participants' within this study. I highlighted how participants often retrospectively recalled the history of their illness and transplant experiences during the first interview, and often reflected on life up to but not including the present moment. It was through further interviews that participants started to acknowledge and come to share their present moment experiences. Here, I discovered how participants' experiences were often not linear and did not follow chronological trajectory. Instead, the experiences shared across the three phases of interviews over the 12-month study duration followed a much more unstructured view of the participants' worlds in response to life events and varying illness experiences which were somewhat disconnected to Transplant Games events.

Overall, this study has moved beyond the 'self' in the self-management and towards an understanding of sport as a psychosocial tool to build and develop illness self-management networks. In doing so, I hope this study will offer future policy makers and practitioners with evidence of the psychosocial impact of sport that moves beyond the well-established physiological benefits. Further, I would encourage future practitioners to consider sport from a psychosocial perspective as a potential tool to aid self-management and rehabilitation for transplant populations.

REFERENCES

Adelman, M. B., Parks, M. R., & Albrecht, T. L. (1987). Beyond close relationships: Support in weak ties. *Communicating social support*, 126-147.

Albrecht, T. L., & Goldsmith, D. J. (2003). Social support, social networks, and health.

Allen-Collinson, J., & Owton, H. (2014). Take a deep breath: Asthma, sporting embodiment, the senses and 'auditory work'. *International review for the sociology of sport, 49*(5), 592-608.

Allen, C., Vassilev, I., Kennedy, A., & Rogers, A. (2016). Long-term condition self-management support in online communities: a meta-synthesis of qualitative papers. *Journal of medical Internet research, 18*(3), e61.

Allen, C., Vassilev, I., Kennedy, A., & Rogers, A. (2020). The work and relatedness of ties mediated online in supporting long-term condition self-management. *Sociology of Health & Illness, 42*(3), 579-595.

Anekwe, T. D., & Rahkovsky, I. (2018). Self-management: A comprehensive approach to management of chronic conditions. *American journal of public health, 108*(S6), S430-S436.

Asbring, P. (2001). Chronic illness–a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of advanced nursing, 34*(3), 312-319.

Atamañuk, A., Fragola, J. O., Casonu, M., Lirio, C., Graziano, V., & Cicora, F. (2017). *Physical Activity Among Organ Recipients: Data Collected From the Latin American Transplant Games.* Paper presented at the Transplantation Proceedings.

Atkinson, M. J., Boltri, J. M., Davis-Smith, M., Seale, J. P., Shellenberger, S., & Gonsalves, D. (2009). A qualitative inquiry into the community and programmatic dimensions associated with successful implementation of church-based diabetes prevention programs. *Journal of Public Health Management and Practice, 15*(3), 264-273.

Aujoulat, I., Janssen, M., Libion, F., Charles, A.-S., Struyf, C., Smets, F., . . . Lerut, J. (2014). Internalizing motivation to self-care: a multifaceted challenge for young liver transplant recipients. *Qualitative Health Research, 24*(3), 357-365.

Bandura, A. (1999). Social cognitive theory: An agentic perspective. *Asian journal of social psychology, 2*(1), 21-41.

Bandura, A., & Walters, R. H. (1977). *Social learning theory* (Vol. 1): Prentice-hall Englewood Cliffs, NJ.

Barbour, R. (2008). *Doing focus groups*: Sage.

Barta, Z., McNamara, J. M., Huszar, D. B., & Taborsky, M. (2011). Cooperation among non-relatives evolves by state-dependent generalized reciprocity. *Proceedings of the royal society B: Biological Sciences, 278*(1707), 843-848.

Bartlett, M. Y., & DeSteno, D. (2006). Gratitude and prosocial behavior: Helping when it costs you. *Psychological science, 17*(4), 319-325.

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The qualitative report, 13*(4), 544-559.

Been-Dahmen, J. M., Grijpma, J. W., Ista, E., Dwarswaard, J., Maasdam, L., Weimar, W., . . . Massey, E. K. (2018). Self-management challenges and support needs among kidney transplant recipients: A qualitative study. *Journal of advanced nursing, 74*(10), 2393-2405.

Bellotti, E. (2014). *Qualitative networks: mixed methods in sociological research*: Routledge.

Bernardi, L., Keim, S., & Von der Lippe, H. (2007). Social influences on fertility: A comparative mixed methods study in Eastern and Western Germany. *Journal of mixed methods research, 1*(1), 23-47.

Bhaskar, R. (1975). A realist theory of science, York. In: Leeds Books Ltd.

Bhaskar, R. (1978). On the possibility of social scientific knowledge and the limits of naturalism. *Journal for the Theory of Social Behaviour*.

Bhaskar, R., & Danermark, B. (2006). Metatheory, interdisciplinarity and disability research: a critical realist perspective. *Scandinavian Journal of Disability Research, 8*(4), 278-297.

Bidart, C., & Lavenu, D. (2005). Evolutions of personal networks and life events. *Social Networks, 27*(4), 359-376.

Bird, C. M. (2005). How I stopped dreading and learned to love transcription. *Qualitative inquiry, 11*(2), 226-248.

Blauwet, C., & Willick, S. E. (2012). The Paralympic Movement: using sports to promote health, disability rights, and social integration for athletes with disabilities. *PM&R, 4*(11), 851-856.

Boase, J., & Wellman, B. (2006). Personal relationships: On and off the Internet. *The Cambridge handbook of personal relationships, 8*, 709-723.
Bobrowski, A. E. (2020). School and sports participation post-transplant. *Pediatric Transplantation*, e13791.
Boddy, C. R. (2016). Sample size for qualitative research. *Qualitative Market Research: An International Journal*.
Boekaerts, M., Zeidner, M., & Pintrich, P. R. (1999). *Handbook of self-regulation*: Elsevier.
Bogue Kerr, S., Soulière, M., & Bell, L. (2018). The transliminal self: The ebb and flow of the kidney transplant experience. *Qualitative Health Research, 28*(4), 561-571.
Borgatti, S. P., Everett, M. G., & Freeman, L. C. (2002). Ucinet for Windows: Software for social network analysis. *Harvard, MA: analytic technologies, 2006*.
Borgatti, S. P., Everett, M. G., & Johnson, J. C. (2018). *Analyzing social networks*: Sage.
Borgatti, S. P., Mehra, A., Brass, D. J., & Labianca, G. (2009). Network analysis in the social sciences. *science, 323*(5916), 892-895.
Borgatti, S. P., & Molina, J.-L. (2005). Toward ethical guidelines for network research in organizations. *Social Networks, 27*(2), 107-117.
Bossy, D., Knutsen, I. R., Rogers, A., & Foss, C. (2016). Institutional logic in self-management support: coexistence and diversity. *Health & social care in the community, 24*(6), e191-e200.
Brandes, U., Freeman, L. C., & Wagner, D. (2013). *Social networks*.
Brandling, J., & House, W. (2009). Social prescribing in general practice: adding meaning to medicine. *Br J Gen Pract, 59*(563), 454-456.
Brännström, M., Ekman, I., Boman, K., & Strandberg, G. (2007). Being a close relative of a person with severe, chronic heart failure in palliative advanced home care–a comfort but also a strain. *Scandinavian Journal of Caring Sciences, 21*(3), 338-344.
Brashers, D. E., Neidig, J. L., & Goldsmith, D. J. (2004). Social support and the management of uncertainty for people living with HIV or AIDS. *Health communication, 16*(3), 305-331.
Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.
Brown, J., Sorrell, J. H., McClaren, J., & Creswell, J. W. (2006). Waiting for a liver transplant. *Qualitative Health Research, 16*(1), 119-136.
Bryman, A. (2016). *Social research methods*: Oxford university press.
Buch-Hansen, H. (2014). Social network analysis and critical realism. *Journal for the Theory of Social Behaviour, 44*(3), 306-325.
Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness, 4*(2), 167-182.
Bury, M., Newbould, J., & Taylor, D. (2005). *A rapid review of the current state of knowledge regarding lay-led self-management of chronic illness: evidence review*: National Institute for Health and Clinical Excellence London.
Carduff, E., Murray, S. A., & Kendall, M. (2015). Methodological developments in qualitative longitudinal research: the advantages and challenges of regular telephone contact with participants in a qualitative longitudinal interview study. *BMC research notes, 8*(1), 142.
Carrington, P. J., Scott, J., & Wasserman, S. (2005). *Models and methods in social network analysis* (Vol. 28): Cambridge university press.
Cavallini, J., Forsberg, A., & Lennerling, A. (2015). Social function after solid organ transplantation: An integrative review. *Nordic Journal of Nursing Research, 35*(4), 227-234.
Chalip, L. (2006). Towards social leverage of sport events. *Journal of sport & tourism, 11*(2), 109-127.
Chang, C. F., Winsett, R. P., Osama Gaber, A., & Hathaway, D. K. (2004). Cost-effectiveness of post-transplantation quality of life intervention among kidney recipients. *Clinical transplantation, 18*(4), 407-414.
Charania, M., & Ickes, W. J. (2006). Research Methods for the Study of Personal Relationships.
Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health & Illness, 5*(2), 168-195.
Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*: Rutgers University Press.

Cho, W., Kim, H., Park, U., Park, W., Yu, J., Yoon, I., . . . Ahn, C. (2017). Rehabilitation of Transplantee and Transplant Games. *The Journal of the Korean Society for Transplantation, 31*(1), 6-15.
Christakis, N. A., & Fowler, J. H. (2007). The spread of obesity in a large social network over 32 years. *New England journal of medicine, 357*(4), 370-379.
Christakis, N. A., & Fowler, J. H. (2009). *Connected: The surprising power of our social networks and how they shape our lives*: Little, Brown Spark.
Cicognani, E., Mazzoni, D., Totti, V., Roi, G. S., Mosconi, G., & Nanni Costa, A. (2015). Health-related quality of life after solid organ transplantation: the role of sport activity. *Psychology, health & medicine, 20*(8), 997-1004.
Cicourel, A. (1964). Interviewing. *Method and measurement in sociology*, 73-104.
Clark, N., Becker, M., Janz, N., Lorig, K., Rakowski, W., & Anderson, L. (1991). Self-management of chronic disease by older adults: a review and questions for research. *Journal of Aging and Health, 3*(1), 3-27.
Clark., A., MacIntyre, P., & Cruickshank, J. (2007). A critical realist approach to understanding and evaluating heart health programmes. *Health:, 11*(4), 513-539.
Cohen, S. (1988). Psychosocial models of the role of social support in the etiology of physical disease. *Health psychology, 7*(3), 269.
Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological bulletin, 98*(2), 310.
Coleman, J. S. (1961). Athletics in high school. *The Annals of the American Academy of Political and Social Science, 338*(1), 33-43.
Coltart, C., & Henwood, K. (2012). On paternal subjectivity: A qualitative longitudinal and psychosocial case analysis of men's classed positions and transitions to first-time fatherhood. *Qualitative Research, 12*(1), 35-52.
Corbin, J. (1987). Accompaniments of chronic illness: Changes in body, self, biography, and biographical time. *Res Sociol Health Care, 6*, 249-281.
Corbin, J., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*: Jossey-Bass.
Corbin, J., & Strauss, A. (1991). A nursing model for chronic illness management based upon the trajectory framework. *Scholarly inquiry for nursing practice, 5*(3), 155-174.
Corbin., J., & Strauss, A. (1985). Managing chronic illness at home: three lines of work. *Qualitative sociology, 8*(3), 224-247.
Cormier, N., Gallo-Cruz, S., & Beard, R. (2017). Navigating the new, transplanted self: How recipients manage the cognitive risks of organ transplantation. *Sociology of Health & Illness, 39*. doi:10.1111/1467-9566.12610
Creer, T. L. (2000). Self-management of chronic illness. In *Handbook of self-regulation* (pp. 601-629): Elsevier.
Crossley, N., & Edwards, G. (2016). Cases, mechanisms and the real: The theory and methodology of mixed-method social network analysis. *Sociological Research Online, 21*(2), 1-15.
Crotty, M. M., Henderson, J., Ward, P. R., Fuller, J., Rogers, A., Kralik, D., & Gregory, S. (2015). Analysis of social networks supporting the self-management of type 2 diabetes for people with mental illness. *BMC health services research, 15*(1), 257.
Crowley-Matoka, M. (2005). Desperately seeking "normal": the promise and perils of living with kidney transplantation. *Social Science & Medicine, 61*(4), 821-831.
Curry, L. A., Shield, R. R., & Wetle, T. T. (2006). *Improving aging and public health research: Qualitative and mixed methods*: American Public Health Association and Gerontological Society of America.
D'angelo, A., Ryan, L., & Tubaro, P. (2016). Visualization in mixed-methods research on social networks. *Sociological Research Online, 21*(2), 1-4.
D'Angelo, A., & Ryan, L. (2019). The presentation of the networked self: Ethics and epistemology in social network analysis. *Social Networks*. doi:https://doi.org/10.1016/j.socnet.2019.06.002
Dean, A., & Lin, N. (1977). The stress-buffering role of social support. *Journal of Nervous and Mental disease*.

Decuypere, M. (2020). Visual Network Analysis: a qualitative method for researching sociomaterial practice. *Qualitative Research, 20*(1), 73-90.
Deliva, R. D., Patterson, C., So, S., Pellow, V., Miske, S., McLister, C., . . . Dipchand, A. I. (2014). The World Transplant Games: an incentive to improve physical fitness and habitual activity in pediatric solid organ transplant recipients. *Pediatric Transplantation, 18*(8), 889-895.
Diaz-Bone, R. (2007). *Review essay: does qualitative network analysis exist?* Paper presented at the Forum Qualitative Sozialforschung/Forum: Qualitative Social Research.
Domínguez, S., & Hollstein, B. (2014). *Mixed Methods Social Networks Research: Design and Applications* (S. Domínguez & B. Hollstein Eds.). Cambridge: Cambridge University Press.
Dominguez, S., & Watkins, C. (2003). Creating networks for survival and mobility: Social capital among African-American and Latin-American low-income mothers. *Social problems, 50*(1), 111-135.
Donati, P. (2010). *Relational sociology: A new paradigm for the social sciences*: Routledge.
Dudley, T., Chaplin, D., Clifford, C., & Mutimer, D. J. (2007). Quality of life after liver transplantation for hepatitis C infection. *Quality of Life Research, 16*(8), 1299-1308.
Dunkel-Schetter, C., & Wortman, C. B. (1982). The interpersonal dynamics of cancer: Problems in social relationships and their impact on the patient. *Interpersonal issues in health care*, 69-100.
Edwards, G. (2010). Mixed-method approaches to social network analysis.
Edwardson, S. R., Dean, K. J., & Brauer, D. J. (1995). Symptom consultation in lay networks in an elderly population. *Journal of Aging and Health, 7*(3), 402-416.
Emirbayer, M., & Goodwin, J. (1994). Network Analysis, Culture, and the Problem of Agency. *American Journal of Sociology, 99*(6), 1411-1454. Retrieved from www.jstor.org/stable/2782580
Engman, A. (2019). Embodiment and the foundation of biographical disruption. *Social Science & Medicine, 225*, 120-127.
Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E., & Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health & Illness, 26*(2), 242-261.
Festinger, L. (1954). A theory of social comparison processes. *Human relations, 7*(2), 117-140.
Figgins, S. G., Smith, M. J., Sellars, C. N., Greenlees, I. A., & Knight, C. J. (2016). "You really could be something quite special": A qualitative exploration of athletes' experiences of being inspired in sport. *Psychology of Sport and Exercise, 24*, 82-91.
Fingerman, K. L. (2009). Consequential strangers and peripheral ties: The importance of unimportant relationships. *Journal of Family Theory & Review, 1*(2), 69-86.
Fisher, E. B., Arfken, C. L., Heins, J. M., Houston, C. A., Jeffe, D. B., & Sykes, R. K. (1997). Acceptance of diabetes regimens in adults. In *Handbook of Health Behavior Research II* (pp. 189-212): Springer.
Forsberg, A., Bäckman, L., & Möller, A. (2000). Experiencing liver transplantation: a phenomenological approach. *Journal of advanced nursing, 32*(2), 327-334.
Forsberg, A., Cavallini, J., Fridh, I., & Lennerling, A. (2016). The core of social function after solid organ transplantation. *Scandinavian Journal of Caring Sciences, 30*(3), 458-465.
Fox, R. C., & Swazey, J. P. (2002). The courage to fail: a social view of organ transplants and dialysis Transaction. *New Brunswick*.
France, A., Bendelow, G., & Williams, S. (2000). A'risky'business: Researching the health beliefs of children and young people. Researching Children's Perspectives. A. Lewis and G. Lindsay. Buckingham. In: Open University Press.
Frank, A. W. (1998). Stories of illness as care of the self: A Foucauldian dialogue. *Health:, 2*(3), 329-348.
Freeman, L. (2004). The development of social network analysis. *A Study in the Sociology of Science, 1*, 687.
Friedkin, N. E. (2006). *A structural theory of social influence* (Vol. 13): Cambridge University Press.
Frost, J., Grose, J., & Britten, N. (2017). A qualitative investigation of lay perspectives of diagnosis and self-management strategies employed by people with progressive multiple sclerosis. *Health:, 21*(3), 316-336.

Fuchs, A., Perrin, C., & Ohl, F. (2014). Using sport to cope with cystic fibrosis. *Loisir et Société/Society and Leisure, 37*(2), 189-204.
Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The qualitative report, 20*(9), 1408.
Gallant, M. P. (2003). The influence of social support on chronic illness self-management: a review and directions for research. *Health education & behavior, 30*(2), 170-195.
Gallant, M. P., Spitze, G., & Grove, J. G. (2010). Chronic illness self-care and the family lives of older adults: A synthetic review across four ethnic groups. *Journal of cross-cultural gerontology, 25*(1), 21-43.
Gallant, M. P., Spitze, G. D., & Prohaska, T. R. (2007). Help or hindrance? How family and friends influence chronic illness self-management among older adults. *Research on aging, 29*(5), 375-409.
Gately, C., Rogers, A., & Sanders, C. (2007). Re-thinking the relationship between long-term condition self-management education and the utilisation of health services. *Social Science & Medicine, 65*(5), 934-945.
Gennep, A. v. (1960). The rites of passage. In: Chicago: University of Chicago Press.
Gillett, J., Cain, R., & Pawluch, D. (2002). Moving beyond the biomedical: The use of physical activity to negotiate illness. *Sociology of Sport Journal, 19*(4), 370-384.
Glaser, B. G., & Strauss, A. L. (1980). *Time for dying*: AldineTransaction.
Glidden, L. M., Bamberger, K. T., Draheim, A. R., & Kersh, J. (2011). Parent and athlete perceptions of Special Olympics participation: Utility and danger of proxy responding. *Intellectual and Developmental Disabilities, 49*(1), 37-45.
Global Observatory on Donation and Transplantation. (2019). Reports. Retrieved from http://www.transplant-observatory.org/reports/
Gould, R. V., & Fernandez, R. M. (1989). Structures of mediation: A formal approach to brokerage in transaction networks. *Sociological methodology*, 89-126.
Grady, P. A., & Gough, L. L. (2014). Self-management: a comprehensive approach to management of chronic conditions. *American journal of public health, 104*(8), e25-e31.
Granovetter, M. (1973). The strength of weak ties. *American Journal of Sociology, 78*(6), 1360-1380.
Granovetter, M. (1977). The strength of weak ties. In *Social Networks* (pp. 347-367): Elsevier.
Granovetter, M. (1983). The strength of weak ties: A network theory revisited. *Sociological theory*, 201-233.
Granovetter, M. (1985). Economic Action and Social Structure: The Problem of Embeddedness. *American Journal of Sociology, 91*(3), 481-510. doi:10.1086/228311
Green, J., & Thorogood, N. (2018). *Qualitative methods for health research*: sage.
Griffin, P. (1990). World Transplant Games--Singapore, 1989. *British journal of sports medicine, 24*(2), 130.
Grossoehme, D., & Lipstein, E. (2016). Analyzing longitudinal qualitative data: the application of trajectory and recurrent cross-sectional approaches. *BMC research notes, 9*(1), 136.
Grumme, V. S., & Gordon, S. C. (2016). Social media use by transplant recipients for support and healing. *CIN: Computers, Informatics, Nursing, 34*(12), 570-577.
Hammersley, M. (1992). Some reflections on ethnography and validity. *Qualitative studies in education, 5*(3), 195-203.
Harwood, L., & Clark, A. M. (2012). Understanding health decisions using critical realism: home-dialysis decision-making during chronic kidney disease. *Nursing inquiry, 19*(1), 29-38.
Health, D. o. (2001). *Expert Patient: A New Approach to Chronic Disease Management for the 21st Century*: DoH London.
Heath, S., Fuller, A., & Johnston, B. (2009). Chasing shadows: defining network boundaries in qualitative social network analysis. *Qualitative Research, 9*(5), 645-661. doi:10.1177/1468794109343631
Heinemann, L. L. (2014). For the sake of others: reciprocal webs of obligation and the pursuit of transplantation as a caring act. *Medical Anthropology Quarterly, 28*(1), 66-84.
Helgeson, V. S., & Novak, S. A. (2007). Illness centrality and well-being among male and female early adolescents with diabetes. *Journal of pediatric psychology, 32*(3), 260-272.

Helgeson, V. S., & Taylor, S. E. (1993). Social Comparisons and Adjustment Among Cardiac Patients 1. *Journal of Applied Social Psychology, 23*(15), 1171-1195.

Herz, A., Peters, L., & Truschkat, I. (2014). *How to do qualitative structural analysis: The qualitative interpretation of network maps and narrative interviews.* Paper presented at the Forum Qualitative Sozialforschung/Forum: Qualitative Social Research.

Hogan, B., Carrasco, J. A., & Wellman, B. (2007). Visualizing personal networks: Working with participant-aided sociograms. *Field Methods, 19*(2), 116-144.

Holloway, I., & Biley, F. C. (2011). Being a qualitative researcher. *Qualitative Health Research, 21*(7), 968-975.

Hollstein, B. (2007). *Qualitative methods in network analysis.* Paper presented at the Seminar on the Quantitative-Qualitative Interface in Social Network Analysis: University of Essex, March 11, Seminar.

Hollstein, B. (2011). Qualitative approaches. *The SAGE handbook of social network analysis*, 404-416.

Hunt, E. R., & Papathomas, A. (2020). Being physically active through chronic illness: life experiences of people with arthritis. *Qualitative Research in Sport, Exercise and Health, 12*(2), 242-255.

Iglesias, K., De Geest, S., Berben, L., Dobbels, F., Denhaerynk, K., Russell, L. C., . . . Peytremann-Bridevaux, I. (2020). Validation of the patient assessment of chronic illness care (PACIC) short form scale in heart transplant recipients: the international cross-sectional bright study. *BMC health services research, 20*(1), 1-11.

James, E., Kennedy, A., Vassilev, I., Ellis, J., & Rogers, A. (2020). Mediating engagement in a social network intervention for people living with a long-term condition: A qualitative study of the role of facilitation. *Health Expectations*.

Janaudis-Ferreira, T., Mathur, S., Deliva, R., Howes, N., Patterson, C., Räkel, A., . . . Avitzur, Y. (2019). Exercise for solid organ transplant candidates and recipients: a joint position statement of the Canadian Society of Transplantation and CAN-RESTORE. *Transplantation, 103*(9), e220-e238.

Janghorban, R., Roudsari, R. L., & Taghipour, A. (2014). Skype interviewing: The new generation of online synchronous interview in qualitative research. *International journal of qualitative studies on health and well-being, 9*(1), 24152.

Jasper, J., Nickerson, C. A., Ubel, P. A., & Asch, D. A. (2004). Altruism, incentives, and organ donation: attitudes of the transplant community. *Medical Care*, 378-386.

Jeffries, M., Mathieson, A., Kennedy, A., Kirk, S., Morris, R., Blickem, C., . . . Rogers, A. (2015). Participation in voluntary and community organisations in the U nited K ingdom and the influences on the self-management of long-term conditions. *Health & social care in the community, 23*(3), 252-261.

Johnson, U., Hinic, H., Billstrom, A., & Gabel, H. (2013). Transplant Recipients' Experience of Participation at the World Transplant Games in Gothenburg 2011: A Study of Psychological Well-being. *The Open Transplantation Journal, 7*(1).

Katz, M., & Heere, B. (2013). Leaders and followers: An exploration of the notion of scale-free networks within a new brand community. *Journal of Sport Management, 27*(4), 271-287.

Katz, M., & Heere, B. (2015). Empowerment within brand communities: Overcoming the Achilles' Heel of scale-free networks. *Sport Management Review, 18*(3), 370-383.

Keim, S., Klärner, A., & Bernardi, L. (2009). Qualifying social influence on fertility intentions: Composition, structure and meaning of fertility-relevant social networks in Western Germany. *Current sociology, 57*(6), 888-907.

Kennedy, A., Rogers, A., & Bower, P. (2007). Support for self care for patients with chronic disease. *Bmj, 335*(7627), 968-970.

Kennedy, A., Vassilev, I., James, E., & Rogers, A. (2015). Implementing a social network intervention designed to enhance and diversify support for people with long-term conditions. A qualitative study. *Implementation science, 11*(1), 27.

Ketokivi, K. (2009). Sharing the same fate: The social bond between the self and fellow sufferers in the context of peer support. *European Societies, 11*(3), 391-410.

Ketokivi, K., & Meskus, M. (2015). The dilemma of 'the capable actor'and the case of disrupted lives. *Contemporary Social Science, 10*(1), 39-51.

Knoke, D. (1990). Networks of political action: Toward theory construction. *Social forces, 68*(4), 1041-1063.
Koch, T., Jenkin, P., & Kralik, D. (2004). Chronic illness self-management: locating the 'self'. *Journal of advanced nursing, 48*(5), 484-492.
Le Hénaff, Y., & Héas, S. (2020). Engagement in leisure and physical activities: analysing the biographical disruptions of a rare chronic disease in France. *Sociology of Health & Illness, 42*(1), 65-79.
Lee, R. M. (1993). *Doing research on sensitive topics*: Sage.
Lerret, S. M., White-Traut, R., Medoff-Cooper, B., Simpson, P., Adib, R., Ahamed, S. I., & Schiffman, R. (2020). Pilot study protocol of a mHealth self-management intervention for family members of pediatric transplant recipients. *Research in nursing & health, 43*(2), 145-154.
Lewis, J. (2007). Analysing Qualitative Longitudinal Research in Evaluations. *Social Policy and Society, 6*(4), 545-556. doi:10.1017/S1474746407003880
Lewis., K., Winsett, R. P., Cetingok, M., Martin, J., & Hathaway, D. K. (2000). Social network mapping with transplant recipients. *Progress in Transplantation, 10*(4), 262-266.
Li, T., & Zhang, Y. (2015). Social network types and the health of older adults: Exploring reciprocal associations. *Social Science & Medicine, 130*, 59-68.
Liben-Nowell, D., & Kleinberg, J. (2007). The link-prediction problem for social networks. *Journal of the American society for information science and technology, 58*(7), 1019-1031.
Litwin, H. (1995). The social networks of elderly immigrants: An analytic typology. *Journal of Aging Studies, 9*(2), 155-174.
Litwin, H. (2001). Social network type and morale in old age. *The Gerontologist, 41*(4), 516-524.
Litwin, H., & Shiovitz-Ezra, S. (2011). Social network type and subjective well-being in a national sample of older Americans. *The Gerontologist, 51*(3), 379-388.
Lo Iacono, V., Symonds, P., & Brown, D. H. (2016). Skype as a tool for qualitative research interviews. *Sociological Research Online, 21*(2), 103-117.
Lock, M. M. (2002). *Twice dead: Organ transplants and the reinvention of death* (Vol. 1): Univ of California Press.
Locock, L., Ziebland, S., & Dumelow, C. (2009). Biographical disruption, abruption and repair in the context of motor neurone disease. *Sociology of Health & Illness, 31*(7), 1043-1058.
Lubbers, M. J., Molina, J. L., Lerner, J., Brandes, U., Ávila, J., & McCarty, C. (2010). Longitudinal analysis of personal networks. The case of Argentinean migrants in Spain. *Social Networks, 32*(1), 91-104.
Lundmark, M., Lennerling, A., Almgren, M., & Forsberg, A. (2016). Recovery after lung transplantation from a patient perspective–proposing a new framework. *Journal of advanced nursing, 72*(12), 3113-3124.
Macdonald, J. H., Kirkman, D., & Jibani, M. (2009). Kidney transplantation: a systematic review of interventional and observational studies of physical activity on intermediate outcomes. *Advances in chronic kidney disease, 16*(6), 482-500.
Marin, A., & Wellman, B. (2011). Social network analysis: An introduction. *The SAGE handbook of social network analysis, 11*.
Martin, S. C., Stone, A. M., Scott, A. M., & Brashers, D. E. (2010). Medical, Personal, and Social Forms of Uncertainty Across the Transplantation Trajectory. *Qualitative Health Research, 20*(2), 182-196. doi:10.1177/1049732309356284
Mathur, S., Janaudis-Ferreira, T., Wickerson, L., Singer, L. G., Patcai, J., Rozenberg, D., . . . Helm, D. (2014). Meeting report: consensus recommendations for a research agenda in exercise in solid organ transplantation. *American Journal of Transplantation, 14*(10), 2235-2245.
Maxwell, J. (1992). Understanding and validity in qualitative research. *Harvard educational review, 62*(3), 279-301.
Maxwell, J. (2017). The validity and reliability of research: A realist perspective. *The BERA/SAGE handbook of educational research, 1*, 116-140.
Mazzoni, D., Cicognani, E., Mosconi, G., Totti, V., Roi, G., Trerotola, M., & Costa, A. N. (2014). *Sport activity and health-related quality of life after kidney transplantation.* Paper presented at the Transplantation proceedings.

McDonough, M. H., Ullrich-French, S., & McDavid, M. L. (2018). Helping kids connect: Participant and staff perspectives on facilitating social relationships in a physical activity-based positive youth development program for youth from low-income families. *Sport, Exercise, and Performance Psychology, 7*(1), 13.

McGee, H. M., & Horgan, J. H. (1996). Participation in the Cardiac Transplant Games: Impact on health-related quality of life. *British Journal of Health Psychology, 1*(3), 245-252.

McNamee, M. (2004). *Philosophy and the sciences of exercise, health and sport: Critical perspectives on research methods*: Routledge.

McPherson, M., Smith-Lovin, L., & Cook, J. M. (2001). Birds of a feather: Homophily in social networks. *Annual review of sociology, 27*(1), 415-444.

Melzer, S. M., Leadbeater, B., Reisman, L., Jaffe, L. R., & Lieberman, K. V. (1989). Characteristics of social networks in adolescents with end-stage renal disease treated with renal transplantation. *Journal of Adolescent Health Care, 10*(4), 308-312.

Meredith, S. J., Wagstaff, C. R., & Dicks, M. (2019). Getting to the heart of the matter: an ethnography of emotions and emotion regulation in cardiac rehabilitation. *Qualitative Research in Sport, Exercise and Health, 11*(3), 364-381.

Merleau-Ponty, M. (2012). Phenomenology of perception (DA Landes, Trans.). *New York*.

Moini, M., Schilsky, M. L., & Tichy, E. M. (2015). Review on immunosuppression in liver transplantation. *World journal of hepatology, 7*(10), 1355.

Moola, F. J., Faulkner, G., White, L., & Kirsh, J. (2015). Kids with special hearts: The experience of children with congenital heart disease at Camp Willowood. *Qualitative Research in Sport, Exercise and Health, 7*(2), 271-293.

Moreno, J. L. (1953). Who shall survive? Foundations of sociometry, group psychotherapy and socio-drama.

Morris, R. L., Kennedy, A., & Sanders, C. (2016). Evolving 'self'-management: exploring the role of social network typologies on individual long-term condition management. *Health Expectations, 19*(5), 1044-1061.

Mosconi, G., Cuna, V., Tonioli, M., Totti, V., Roi, G. S., Sarto, P., . . . Costa, A. N. (2014). Physical activity in solid organ transplant recipients: preliminary results of the Italian project. *Kidney and Blood Pressure Research, 39*(2-3), 220-227.

Mosconi., G., Roi, G., & Stefoni, S. (2011). Physical activity and renal transplantation. *Giornale Italiano di Nefrologia: Organo Ufficiale Della Societa Italiana di Nefrologia, 28*(2), 174-187.

Newbould, J., Taylor, D., & Bury, M. (2006). Lay-led self-management in chronic illness: a review of the evidence. *Chronic illness, 2*(4), 249-261.

NHS. (2020). Statistics about organ donation. Retrieved from https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/statistics-about-organ-donation/

Nilsson, M., Persson, L. O., & Forsberg, A. (2008). Perceptions of experiences of graft rejection among organ transplant recipients striving to control the uncontrollable. *Journal of clinical nursing, 17*(18), 2408-2417.

Nimrod, G., Kleiber, D. A., & Berdychevsky, L. (2012). Leisure in coping with depression. *Journal of Leisure Research, 44*(4), 419-449.

Nissim, R., Gagliese, L., & Rodin, G. (2009). The desire for hastened death in individuals with advanced cancer: a longitudinal qualitative study. *Social Science & Medicine, 69*(2), 165-171.

Novak, M., Costantini, L., Schneider, S., & Beanlands, H. (2013). *Approaches to self-management in chronic illness.* Paper presented at the Seminars in dialysis.

Nowak, M. A., & Roch, S. (2007). Upstream reciprocity and the evolution of gratitude. *Proceedings of the royal society B: Biological Sciences, 274*(1610), 605-610.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods, 16*(1), 1609406917733847.

O'Brien, G. M., Donaghue, N., Walker, I., & Wood, C. A. (2014). Deservingness and gratitude in the context of heart transplantation. *Qualitative Health Research, 24*(12), 1635-1647.

O'malley, A. J., & Marsden, P. V. (2008). The analysis of social networks. *Health services and outcomes research methodology, 8*(4), 222-269.

Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The qualitative report, 13*(4), 695-705.
Osborne, R. H., Jordan, J. E., & Rogers, A. (2008). A critical look at the role of self-management for people with arthritis and other chronic diseases. *Nature Clinical Practice Rheumatology, 4*(5), 224-225.
Ouellette, A., Achille, M., & Pâquet, M. (2009). The experience of kidney graft failure: patients' perspectives. *Qualitative Health Research, 19*(8), 1131-1138.
Owton, H., & Allen-Collinson, J. (2016). Conformers, contesters, creators: vignettes of asthma identities and sporting embodiment. *International review for the sociology of sport, 51*(6), 699-714.
Painter, P., & Marcus, R. L. (2013). Assessing physical function and physical activity in patients with CKD. *Clinical Journal of the American Society of Nephrology, 8*(5), 861-872.
Paisley, K., Jostad, J., Sibthorp, J., Pohja, M., Gookin, J., & Rajagopal-Durbin, A. (2014). Considering students' experiences in diverse groups: Case studies from the national outdoor leadership school. *Journal of Leisure Research, 46*(3), 329-341.
Parkes, C. M. (1971). Psycho-social transitions: a field for study. *Social Science & Medicine*.
Patton, M. Q. (1990). *Qualitative evaluation and research methods*: SAGE Publications, inc.
Perks, T. (2007). Does sport foster social capital? The contribution of sport to a lifestyle of community participation. *Sociology of Sport Journal, 24*(4), 378-401.
Perry, B. L., & Pescosolido, B. A. (2012). Social network dynamics and biographical disruption: The case of "first-timers" with mental illness. *American Journal of Sociology, 118*(1), 134-175.
Piana, N., Maldonato, A., Bloise, D., Carboni, L., Careddu, G., Fraticelli, E., . . . Romani, G. (2010). The narrative-autobiographical approach in the group education of adolescents with diabetes: a qualitative research on its effects. *Patient education and counseling, 80*(1), 56-63.
Piette, J. D., Rosland, A. M., Silveira, M., Kabeto, M., & Langa, K. M. (2010). The case for involving adult children outside of the household in the self-management support of older adults with chronic illnesses. *Chronic illness, 6*(1), 34-45.
Ponton, P., Rupolo, G., Marchini, F., Feltrin, A., & Perin, N. (2001). *Quality-of-life change after kidney transplantation.* Paper presented at the Transplantation proceedings.
Portillo, M. C., Regaira, E., Pumar-Méndez, M. J., Mujika, A., Vassilev, I., Rogers, A., . . . Todorova, E. (2015). Voluntary organizations and community groups as new partners in diabetes self-management and education: a critical interpretative synthesis. *The Diabetes Educator, 41*(5), 550-568.
Poucher, Z. A., Tamminen, K. A., & Kerr, G. (2018). Providing social support to female Olympic athletes. *Journal of Sport and Exercise Psychology, 40*(4), 217-228.
Prell, C. (2012). *Social network analysis: History, theory and methodology*: Sage.
Ravizza, D. (2010). The uses of sport for children in armed conflict. *Journal of Sport Science and Physical*.
Reeves, D., Blickem, C., Vassilev, I., Brooks, H., Kennedy, A., Richardson, G., & Rogers, A. (2014). The contribution of social networks to the health and self-management of patients with long-term conditions: a longitudinal study. *PloS one, 9*(6), e98340.
Richardson, E. V., Barstow, E. A., & Motl, R. W. (2019). A narrative exploration of the evolving perception of exercise among people with multiple sclerosis. *Qualitative Research in Sport, Exercise and Health, 11*(1), 119-137.
Richardson, J., Ong, B., & Sim, J. (2006). Is chronic widespread pain biographically disruptive? *Social Science & Medicine, 63*(6), 1573-1585.
Riessman, C. K. (1993). *Narrative analysis* (Vol. 30): Sage.
Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (2013). *Qualitative research practice: A guide for social science students and researchers*: sage.
Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative research in psychology, 11*(1), 25-41.
Roche, M. (2002). *Megaevents and modernity: Olympics and expos in the growth of global culture*: Routledge.
Rogers, A. (2009). Advancing the expert patient? *Primary Health Care Research & Development, 10*(3), 167-176.

Rogers, A., Brooks, H., Vassilev, I., Kennedy, A., Blickem, C., & Reeves, D. (2014). Why less may be more: a mixed methods study of the work and relatedness of 'weak ties' in supporting long-term condition self-management. *Implementation science, 9*(1), 1-11.

Rogers, A., Gately, C., Kennedy, A., & Sanders, C. (2009). Are some more equal than others? Social comparison in self-management skills training for long-term conditions. *Chronic illness, 5*(4), 305-317.

Rogers, A., Vassilev, I., Sanders, C., Kirk, S., Chew-Graham, C., Kennedy, A., . . . Reeves, D. (2011). Social networks, work and network-based resources for the management of long-term conditions: a framework and study protocol for developing self-care support. *Implementation science, 6*(1), 1-7.

Roi, G., Parigino, M., Pisoni, D., Mosconi, G., Costa, A. N., & Stefoni, S. (2010). Energy expenditure during a day of sport competitions in kidney transplant recipients. *Transplantation, 90*(10), 1136-1138.

Roi, G., Stefoni, S., Mosconi, G., Brugin, E., Burra, P., Ermolao, A., . . . Nacchia, F. (2014). *Physical activity in solid organ transplant recipients: organizational aspects and preliminary results of the Italian project.* Paper presented at the Transplantation proceedings.

Ronkainen, N. J., Tikkanen, O., Littlewood, M., & Nesti, M. S. (2015). An existential perspective on meaning, spirituality and authenticity in athletic careers. *Qualitative Research in Sport, Exercise and Health, 7*(2), 253-270.

Ronkainen, N. J., & Wiltshire, G. (2019). Rethinking validity in qualitative sport and exercise psychology research: a realist perspective. *International Journal of Sport and Exercise Psychology*, 1-16.

Rosland, A.-M., Heisler, M., Choi, H.-J., Silveira, M. J., & Piette, J. D. (2010). Family influences on self-management among functionally independent adults with diabetes or heart failure: do family members hinder as much as they help? *Chronic illness, 6*(1), 22-33.

Ryan, L. (2011). Migrants' social networks and weak ties: accessing resources and constructing relationships post-migration. *The Sociological Review, 59*(4), 707-724.

Ryan, L., & D'Angelo, A. (2018). Changing times: Migrants' social network analysis and the challenges of longitudinal research. *Social Networks, 53*, 148-158.

Ryan, L., Sales, R., Tilki, M., & Siara, B. (2008). Social networks, social support and social capital: The experiences of recent Polish migrants in London. *Sociology, 42*(4), 672-690.

Saldaña, J. (2003). *Longitudinal qualitative research: Analyzing change through time*: Rowman Altamira.

Sandelowski, M. (1995). Sample size in qualitative research. *Research in nursing & health, 18*(2), 179-183.

Sanders, C., Rogers, A., Gardner, C., & Kennedy, A. (2011). Managing 'difficult emotions' and family life: exploring insights and social support within online self-management training. *Chronic illness, 7*(2), 134-146.

Sanders, C., Rogers, A., Gately, C., & Kennedy, A. (2008). Planning for end of life care within lay-led chronic illness self-management training: the significance of 'death awareness' and biographical context in participant accounts. *Social Science & Medicine, 66*(4), 982-993.

Sanderson, T., Calnan, M., Morris, M., Richards, P., & Hewlett, S. (2011). Shifting normalities: interactions of changing conceptions of a normal life and the normalisation of symptoms in rheumatoid arthritis. *Sociology of Health & Illness, 33*(4), 618-633.

Sayer, A. (2000). 2000: Realism and social science. London: Sage.

Schneider, J. W., Conrad, P., & Gallagher, E. B. (2011). Family Care Work and Duty in a "Modern" Chinese Hospital'. *Health and Health Care in Developing Countries: Sociological Perspectives*, 154.

Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., . . . Whittemore, R. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship, 44*(2), 136-144.

Schulz, K.-H., & Kroencke, S. (2015). Psychosocial challenges before and after organ transplantation. *Transplant Research and Risk Management, 7*, 45-58.

Schwalbe, M. L., & Wolkomir, M. (2002). Interviewing men. *Handbook of interview research: Context & Method, Thousand Oaks, Ca: Sage*, 203-219.

Scientific Registry of Transplant Recipients. (2017). OPTN/SRTR 2017 Annual Data Report. Retrieved from https://srtr.transplant.hrsa.gov/annual_reports/2017/Introduction.aspx
Scott, J. (2011). Social network analysis: developments, advances, and prospects. *Social network analysis and mining, 1*(1), 21-26.
Sharp, L. A. (2006). *Strange harvest: Organ transplants, denatured bodies, and the transformed self*: Univ of California Press.
Shaw, R. (2015). Being-in-dialysis: The experience of the machine–body for home dialysis users. *Health, 19*(3), 229-244. doi:10.1177/1363459314539775
Shaw., J., Brown, J., Khan, B., Mau, M. K., & Dillard, D. (2013). Resources, roadblocks and turning points: a qualitative study of American Indian/Alaska Native adults with type 2 diabetes. *Journal of community health, 38*(1), 86-94.
Shildrick, M., McKeever, P., Abbey, S., Poole, J., & Ross, H. (2009). Troubling dimensions of heart transplantation. *Medical Humanities, 35*(1), 35-38.
Sitch, M., & Lowry, R. G. (2019). Social influence on students' experiences of transition into postgraduate study. *Sport and Exercise Psychology Review, 15*(1).
Slapak, M. (2005). Sport and transplantation. *Annals of transplantation, 10*(1), 60-67.
Smith, B., & McGannon, K. R. (2018). Developing rigor in qualitative research: Problems and opportunities within sport and exercise psychology. *International review of sport and exercise psychology, 11*(1), 101-121.
Smith, K., & Christakis, N. (2008). Social networks and health. *Annu. Rev. Sociol, 34*, 405-429.
Smith., B. (2013). Disability, sport and men's narratives of health: A qualitative study. *Health psychology, 32*(1), 110.
Sontag, S. (1978). Illness as Metaphor: Farrar. *Straus and Giroux, 87*.
Sparkes, A. C., & Smith, B. (2013). *Qualitative research methods in sport, exercise and health: From process to product*: Routledge.
Spencer, L., & Pahl, R. (2006). *Rethinking friendship: Hidden solidarities today*: Princeton University Press.
Sque, M., & Payne, S. A. (1994). Gift Exchange Theory: a critique in relation to organ transplantation. *Journal of advanced nursing, 19*(1), 45-51.
Stoller, E. P., & Wisniewski, A. A. (2003). The structure of lay consultation networks: managing illness in community settings. *Journal of Aging and Health, 15*(3), 482-507.
Stoumpos, S., Jardine, A. G., & Mark, P. B. (2015). Cardiovascular morbidity and mortality after kidney transplantation. *Transplant International, 28*(1), 10-21.
Svenaeus, F. (2012). Organ transplantation and personal identity: how does loss and change of organs affect the self? *Journal of Medicine and Philosophy, 37*(2), 139-158.
Thomson, R., Henderson, S., & Holland, J. (2003). Making the most of what you've got? Resources, values and inequalities in young women's transitions to adulthood. *Educational review, 55*(1), 33-46.
Thomson, R., & McLeod, J. (2015). New frontiers in qualitative longitudinal research: an agenda for research. *International Journal of Social Research Methodology, 18*(3), 243-250.
Tilden, B., Charman, D., Sharples, J., & Fosbury, J. (2005). Identity and adherence in a diabetes patient: Transformations in psychotherapy. *Qualitative Health Research, 15*(3), 312-324.
Tobin, D. L., Reynolds, R. V., Holroyd, K. A., & Creer, T. L. (1986). Self-management and social learning theory. *Self-management of chronic disease: Handbook of clinical interventions and research*, 29-55.
Tolleson, A., & Zeligman, M. (2019). Creativity and Posttraumatic Growth in Those Impacted by a Chronic Illness/Disability. *Journal of Creativity in Mental Health, 14*(4), 499-509.
Tong, A., Chapman, J. R., Wong, G., Kanellis, J., McCarthy, G., & Craig, J. C. (2012). The motivations and experiences of living kidney donors: a thematic synthesis. *American Journal of Kidney Diseases, 60*(1), 15-26.
Tong, A., Morton, R., Howard, K., McTaggart, S., & Craig, J. C. (2011). "When I had my transplant, I became normal." Adolescent perspectives on life after kidney transplantation. *Pediatric Transplantation, 15*(3), 285-293.
Townsend, A., Wyke, S., & Hunt, K. (2006). Self-managing and managing self: practical and moral dilemmas in accounts of living with chronic illness. *Chronic illness, 2*(3), 185-194.

Transplant Sport UK. (2020). British Transplant Games. Retrieved from https://transplantsport.org.uk/btg/
Trusson, D., Pilnick, A., & Roy, S. (2016). A new normal?: Women's experiences of biographical disruption and liminality following treatment for early stage breast cancer. *Social Science & Medicine, 151*, 121-129.
Tubaro, P., Ryan, L., & D'angelo, A. (2016). The visual sociogram in qualitative and mixed-methods research. *Sociological Research Online, 21*(2), 1-18.
Ummel, D., & Achille, M. (2016). Transplant trajectory and relational experience within living kidney dyads. *Qualitative Health Research, 26*(2), 194-203.
Valente, T. W. (2010). *Social networks and health: Models, methods, and applications*: Oxford University Press.
Van Gennep, A. (2019). *The rites of passage*: University of Chicago Press.
Vassilev, I., Band, R., Kennedy, A., James, E., & Rogers, A. (2019). The role of collective efficacy in long-term condition management: A metasynthesis. *Health & social care in the community, 27*(5), e588-e603.
Vassilev, I., Rogers, A., Blickem, C., Brooks, H., Kapadia, D., Kennedy, A., . . . Reeves, D. (2013). Social networks, the 'work'and work force of chronic illness self-management: a survey analysis of personal communities. *PloS one, 8*(4), e59723.
Vassilev, I., Rogers, A., Kennedy, A., & Koetsenruijter, J. (2014). The influence of social networks on self-management support: a metasynthesis. *BMC public health, 14*(1), 719.
Vassilev, I., Rogers, A., Kennedy, A., Oatley, C., & James, E. (2019). Identifying the processes of change and engagement from using a social network intervention for people with long-term conditions. A qualitative study. *Health Expectations, 22*(2), 173-182.
Vassilev, I., Rogers, A., Kennedy, A., Wensing, M., Koetsenruijter, J., Orlando, R., . . . Culliford, D. (2016). Social network type and long-term condition management support: a cross-sectional study in six European countries. *PloS one, 11*(8), e0161027.
Vassilev, I., Rogers, A., Sanders, C., Kennedy, A., Blickem, C., Protheroe, J., . . . Morris, R. (2011). Social networks, social capital and chronic illness self-management: a realist review. *Chronic illness, 7*(1), 60-86.
Venturini, T., Jacomy, M., & Jensen, P. (2019). What Do We See When We Look at Networks. An Introduction to Visual Network Analysis and Force-Directed Layouts. *An Introduction to Visual Network Analysis and Force-Directed Layouts (April 26, 2019)*.
Venturini, T., Jacomy, M., & Pereira, D. (2014). Visual network analysis. *Sciences Pomedialab*.
Vohs, K. D., & Baumeister, R. F. (2016). *Handbook of self-regulation: Research, theory, and applications*: Guilford Publications.
Wainwright, S. P. (1995). The transformational experience of liver transplantation. *Journal of advanced nursing, 22*(6), 1068-1076. doi:10.1111/j.1365-2648.1995.tb03107.x
Waldron, R., Malpus, Z., Shearing, V., Sanchez, M., & Murray, C. D. (2017). Illness, normality and identity: the experience of heart transplant as a young adult. *Disability and rehabilitation, 39*(19), 1976-1982.
Walker, R. C., Naicker, D., Kara, T., & Palmer, S. C. (2019). Parents' perspectives and experiences of kidney transplantation in children: A qualitative interview study. *Journal of renal care, 45*(3), 193-200.
Welch, L., Orlando, R., Lin, S. X., Vassilev, I., & Rogers, A. (2020). Findings from a pilot randomised trial of a social network self-management intervention in COPD. *BMC Pulmonary Medicine, 20*(1), 1-14.
Wellman, B., Wong, R. Y.-l., Tindall, D., & Nazer, N. (1997). A decade of network change: Turnover, persistence and stability in personal communities. *Social Networks, 19*(1), 27-50.
Weng, L. C., Dai, Y. T., Huang, H. L., & Chiang, Y. J. (2010). Self-efficacy, self-care behaviours and quality of life of kidney transplant recipients. *Journal of advanced nursing, 66*(4), 828-838.
Wenger, G. C. (1987). *Support Networks: Change and Stability: Second Report of a Follow-up Study of Old Elderly People in North Wales*: University College of North Wales, Centre for Social Policy Research and ….
Wenger, G. C. (1991). A network typology: From theory to practice. *Journal of Aging Studies, 5*(2), 147-162.

White, H. (1992). Identity and control: A structural theory of social action.
Wicks, M. N., Milstead, E. J., Hathaway, D. K., & Cetingok, M. (1998). Family caregivers' burden, quality of life, and health following patients' renal transplantation. *Journal of transplant coordination, 8*(3), 170-176.
Williams, C., & Stevens, D. (2013). Physical activity and exercise training in young people with cystic fibrosis: Current recommendations and evidence. *Journal of Sport and Health Science, 2*(1), 39-46.
Williams., S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness, 22*(1), 40-67.
Wilson, S. (2007). 'When you have children, you're obliged to live'1: motherhood, chronic illness and biographical disruption. *Sociology of Health & Illness, 29*(4), 610-626.
Wiltshire, G. (2018). A case for critical realism in the pursuit of interdisciplinarity and impact. *Qualitative Research in Sport, Exercise and Health, 10*(5), 525-542.
Wochna, V. (1997). Anxiety, needs, and coping in family members of the bone marrow transplant patient. *Cancer nursing, 20*(4), 244-250.
Wood, A. M., Maltby, J., Gillett, R., Linley, P. A., & Joseph, S. (2008). The role of gratitude in the development of social support, stress, and depression: Two longitudinal studies. *Journal of Research in personality, 42*(4), 854-871.
World Health Organization. (2019). Human organ transplantation. Retrieved from https://www.who.int/transplantation/organ/en/
World Transplant Games Federation. (2019). Refit for life! Retrieved from https://wtgf.org/refitforlife/
Wray, J., & Lunnon-Wood, T. (2008). Psychological benefits for children and adolescents who have undergone transplantation of the heart from participation in the British Transplant Games. *Cardiology in the Young, 18*(2).
Wright, K. B., Rains, S., & Banas, J. (2010). Weak-tie support network preference and perceived life stress among participants in health-related, computer-mediated support groups. *Journal of Computer-Mediated Communication, 15*(4), 606-624.
Yin, R. K. (2009). How to do better case studies. *The SAGE handbook of applied social research methods, 2*, 254-282.
Yin, R. K. (2018). Case study research and applications. In: Sage.